CHAPTER

22 Language and Communication in People Who Are Deafblind

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Abstract

The development of language and communication in people who are deafblind requires child rearing, interaction, and teaching methods that match each individual's cognitive development, level of functioning, and interest; that can be perceived on a sensory level; that provoke responses that match the individual's linguistic and motoric level; and that also fit with the language and communication skills and resources of people around them. This chapter describes all these different aspects of language and communication in children who are congenitally deafblind (and who seldom acquire symbolic communication) as well as people with acquired deafblindness. It also gives an overview of the way access to communication and language can be accommodated, including assessment, augmented and alternative communication, and staff training.

Key Words: deafblindness, tactile signing, dual sensory impairment, video interaction analysis, augmented and alternative communication, intersubjectivity, tangible symbols

The world association promoting services for people with deafblindness, DeafBlind International, uses the term "deafblindness" to refer to people with varied combinations of visual and hearing disabilities (DeafBlind International, 2014). This chapter deals with the language and communication challenges people who are deafblind meet. First, some definitional issues and some examples of causes of deafblindness are described to set the stage for descriptions of how deafblindness affects language, communication, and other developmental domains; how to assess language and communication; and, finally, how to promote language and communication in people who are deafblind.

The term "deafblind" covers not only people who are completely deaf and blind but also those with various gradations of visual and hearing disabilities, that is, deafness combined with partial sightedness, blindness combined with partial hearing loss, and partial sightedness combined with partial hearing loss. The amount of functional vision and hearing that a person with deafblindness has, his or her so-called residuals, influences the development of language and communication at least in part by determining what modality of language input can be perceived. Fellinger, Holzinger, Dirmhirn, van Dijk, and Goldberg (2009) distinguished four subgroups on the basis of these residuals: (1) people with some functional hearing, but no functional vision; (2) people with some functional vision, but no functional hearing; (3) people with both some functional vision and hearing, and (4) people with no functional vision or hearing. In people with dual sensory loss, but with some functional hearing and/or vision, their residual sensory modalities can be used for linguistic and communication practices. This is an advantage in comparison with people who have no vision and hearing left. For instance, the first and third group described earlier may be able to communicate through spoken language. Whereas the first group will miss all visually based communication information, the third group will miss only some of this information. The second group, those with functional vision only, may be able to

communicate by means of sign language, while the fourth group, people totally blind and completely deaf, may be limited to tactual sign language. The level of communication skills attained, however, will be heavily affected by the level of intellectual abilities of the person, the amount of special training received, and whether before the onset of the deafblindness the person learned to communicate by verbal or signed language.

With regard to the definition of deafblindness, Ask Larsen and Damen (2014) state that there is heterogeneity in definitions and inclusion criteria of deafblindness. In their study of the literature, two types of definitions were found: "medical/functional" definitions and "ability/functioning" definitions. Definitions that were medical/functional were based on sensory impairment measures. Deafblindness was then defined according to the criteria for visual impairment and hearing impairment such as formulated by the World Health Organization (2001). In contrast, the ability/functioning definitions consider the total outcome of deafblindness on ability and functioning in relation to communication, access to information, and mobility (Ask Larsen & Damen, 2014).

In line with the ability/functioning definition of deafblindness, the term "deafblindness" is used to emphasize that living with a dual sensory loss is a unique and complex form of existence. It acknowledges that having disabilities in the functions of both sight and hearing involves more than just the sum of the two disabilities (Damen & Worm, 2013; Knoors & Vervloed, 2011). People with these combined functional disabilities always have major challenges in learning, getting information, communication, and orientation and mobility (DeafBlind International, 2014). The severity of the challenges people with deafblindness face is not only determined by the degree of hearing and vision loss but also by the age at which the combination of visual and hearing disabilities manifests itself for the first time. Based on age of onset, three types of deafblindness are generally distinguished: (1) congenital deafblindness: the combination of visual and hearing disabilities is developed before birth, is present from birth, or is acquired before language development starts, which is usually within the first year (Dammeyer, 2010); (2) acquired deafblindness: the combination of visual and hearing disabilities occurs after the start of language development (Dammeyer, 2010); and (3) elderly deafblindness: a form of acquired deafblindness where the age of onset is after age 55 (Vaal et al., 2007). The last type of deafblindness is most common.

Since the term "deafblindness" does not necessarily imply that a person has a total lack of vision and hearing, the term can be confusing. People with co-occurring visual and hearing disabilities often do not consider themselves as people with deafblindness. Also relatives, friends, and professionals that are involved with them often do not consider these people as "deafblind," when they have some residual hearing and/or vision. Unfortunately, deafblindness is often also not recognized, partly because professionals are unaware of symptoms of hearing and sight loss but also because several symptoms (e.g., unresponsiveness) overlap with symptoms of other disabilities (Fellinger et al., 2009). There is also the risk that for people with vision and/or hearing residuals, the impact of dual sensory loss is underestimated. Partially hearing people, for example, may be able to perceive and use spoken language. However, they still can experience a lack of contingency and coherence between the experienced world and language input if no special attention is given to their sensory disabilities. An implication of this is that people with deafblindness may not get optimal support. This, in turn, can lead to severe developmental delays, behavioral problems, and/or social isolation (see Damen & Worm, 2013; Knoors & Vervloed, 2011).

Etiologies and Associated Characteristics

People with deafblindness form a heterogeneous group (Dammeyer, 2014) because of differences in age of onset of the visual and auditory disabilities and the presence of other disabilities, such as intellectual and physical disabilities (Carvill, 2001). Differences among deafblind people may be related to differences in the causes of their condition. Common causes of congenital deafblindness include premature birth or a lack of oxygen during birth. People who have congenital deafblindness as a result of problems around birth often have brain damage, and their sensory disabilities are associated with this damage. Vision loss in premature babies can, however, also be caused by damages in the developing retina as a result of high levels of oxygen provided to them in the hospital. Furthermore, hearing loss in premature babies can be caused by antibiotics that are provided to combat infections (Damen & Worm, 2013).

Besides perinatal problems, there are four main causes of dual sensory loss: prenatal infections, syndromes, diseases, and aging. A well-known

infection that can cause congenital deafblindness is rubella, also known as "German measles." If a pregnant woman becomes infected with rubella/German measles, her fetus can suffer developmental delay and severe deformities (Duszak, 2009; O'Donnell, 1996). The earlier the infection occurs in pregnancy, the greater the risk of malformations (Spreen, Risser, & Edgell, 1984) and the greater the severity of these malformations. Children born after being infected with rubella during pregnancy are referred to as people with congenital rubella syndrome (CRS). They often have abnormalities of their ears and eyes and, in addition, can have intellectual disabilities and medical problems such as heart defects and growth retardation (Duszak, 2009; Van Dijk, 1982). In the 21st century, rubella vaccinations are being provided in most but not all countries in the world.

There are several congenital syndromes that cause deafblindness and are associated with specific chromosomal abnormalities. Examples are Down, Norrie, CHARGE, and Usher syndrome. Syndromes are usually associated with specific symptoms. Down syndrome, for example, is well known for the associated typical features and intellectual disabilities. Less well known is that people with Down syndrome often have abnormalities in the eyes and ears that can cause deafblindness. Norrie's disease can be inherited by males only. A common symptom is blindness at birth or soon after birth as a result of an abnormal development of the retina. About one third of individuals with Norrie disease develop progressive hearing loss. Other problems may include intellectual disabilities and motor problems. CHARGE syndrome is very complex, and people with the syndrome can have a varied combination of disabilities. The name CHARGE is an acronym for a combination of symptoms seen in a number of children with this syndrome, including eye malformations (coloboma), heart defects, abnormalities of the passage from nose to throat (atresia of the choanae), retardation of growth and/or development, genital and/or urinary abnormalities, and ear abnormalities and deafness. Almost all children with CHARGE have problems with balance. Usher syndrome is associated with acquired deafblindness. People with this syndrome can be born deaf (type I), with some hearing loss (type II), or with intact hearing (type III) but progressive hearing loss during childhood and adolescence. Later in life, they develop visual disabilities that are the result of a progressive deterioration of the retina. The result of this deterioration is that they have poor vision at night or in dim light (night blindness), and they suffer from progressive loss of peripheral vision, which means that their visual field narrows as they grow older.

Meningitis and strokes are diseases that can lead to deafblindness as well, both in children as well as adults. There are other diseases that can also lead to deafblindness as a result of brain damage, such as a brain tumor. In elderly people, diseases in ears and eyes can cause dual sensory loss. Typical elderly diseases in the eyes are glaucoma, retinitis pigmentosa, and macular degeneration. Hearing loss in elderly people is often caused by deterioration of the nerve cells in the cochlea and/or long-term exposure to excessively loud noises. Both can cause specific loss in the higher tone frequencies that are important for speech detection and discrimination.

Communication and Deafblindness

Before the challenges caused by deafblindness are summarized, a brief summary of issues concerning communication and deafblindness is given. Researchers have used various models to describe and explain communication processes between individuals, for example as a transfer in which communicators either send or receive information (Shannon & Weaver, 1949) or as a dialogue in which communication partners mutually co-construct meaning (Linell, 1998). Janssen and colleagues (Janssen, Riksen-Walraven, & Van Dijk, 2003, p. 198) formulated the following definition of communication: "a form of interaction in which meaning is transmitted and shared by the use of utterances that are perceived, interpreted and negotiated by both partners." This definition describes communication as a dynamic interplay between communication partners. Furthermore, it does not restrict communication to commonly used forms, such as speech or writing. This definition also emphasizes meaning making as what distinguishes communication from other types of social interactions.

The importance of communication for human beings is emphasized by several researchers who have studied the interpersonal communication between infants and their mothers (e.g., Golinkoff, 1986; Tomasello, Carpenter, Call, Behne, & Moll, 2005; Trevarthen & Aitken, 2001). These researchers revealed that communication is an innate ability. Already in newborns, communicative competences can be observed when they interact with familiar caregivers. However, it is through interaction with other people that children further develop these competences. Linguistic skills are part of this

development. By interacting with other people, children acquire the formal properties of signs and symbols and the relationships between them, what they represent, and how language is used pragmatically. Children also gradually learn to take the perspective of the listener (Eilan, Hoerl, McCormack, & Roessler, 2005).

Levels of Communication

In individuals with congenital deafblindness, communication development is often delayed (Bruce, 2005a; Dammeyer, 2010; Mar & Sall, 1994). In typical development, children naturally develop three levels of complexity in communication: (1) body-centered communication/ communication at a sensational level; (2) concrete communication/ communication at a presentational level (i.e., the object where the communication is about is present); and (3) symbolic communication/communication at a representational level (see also Bruce, 2005a; Damen & Worm, 2013; McInnes, 1999; Miles & Rigio, 1999). Many individuals with congenital deafblindness, however, never achieve the highest level of communication development: the level of symbolic communication.

The most basic level of communication, that of body-centered communication, for instance laughing, crying, or vigorous body movements to show fear or excitement, is often observed in infants and in people with deafblindness with profound cognitive delays. This level is also seen in people with congenital deafblindness who have not received special deafblind education or support. However, this does not mean that they do not have the intellectual capacities to develop higher levels of communication. Individuals with a body-centered/sensational level of communication understand what is immediately experienced through the body. Their social partners must observe their bodily reactions to understand how they feel and what they may need.

At a concrete communication level, a person understands that one aspect in the world can be presented by something else, but only when there is a clear connection between the form and the content. An empty drinking cup, for example, can tell someone at a concrete communication level that he gets something to drink. People with deafblindness that function at this communication level are often able to learn iconic signs that are used on a regular basis. These are signs that are quite similar to the action or the shape of what they refer to. Examples are the formal signs for drinking and eating, since they are similar to actual drinking and eating actions. A concrete level of communication is often used by young children (between 9 months and 2 years of age), in people with deafblindness with severe to moderate cognitive delays, and in people with congenital deafblindness who received no or limited special deafblind education or support (Rowland & Stremel-Campbell, 1987).

The highest level of communication is that of symbolic communication. Communication at this level is abstract, which means that there is not a clear connection between the form and the content. What it represents cannot be understood by looking at the form of the representation. Symbolic/representational communication is used by typically developing children from the age of 1 1/2 years and in higher functioning children and adults with deafblindness (Rowland & Stremel-Campbell, 1987). This level of communication includes most words, many manual signs, and written representations.

Communication Modes and Functions

Two other aspects of language and communication are also important: form, or mode, and function. The mode represents the way communication forms are perceived and expressed: the auditory, the visual, or the tactile modality. Speech is a communication form that is perceived primarily through the auditory modality. Photos, pictograms, and sign language make use of the visual modality, whereas tactile sign language, tactile graphics, and body pointing make use of the tactile modality. The choice for a specific modality will be highly dependent on the amount of visual and hearing residuals an individual has. Individuals with congenital deafblindness can also have personal preferences. Many of them will use more than one modality. However, it can be difficult for them to combine multiple modalities at the same time. Furthermore, residual visual and auditory abilities may be insufficient for a person who is deafblind to experience coherence between a referent and that what it refers to in the world. In many individuals with congenital deafblindness, communication forms in the visual and auditory modalities need to be supported by use of the tactile modality.

When analyzing communication in individuals with deafblindness, it can be relevant to consider what the purpose or function is of their communication. According to Granlund and Olson (1993), six different types of purposes can be distinguished. These purposes are referred to as "communicative functions" and consist of (a) joint attention, (b) behavioral regulation, (c) refusing something,

(d) getting something, (e) social interaction, and (f) getting information. According to Rødbroe and Souriau (1999), individuals with congenital deafblindness often do not show communication functions other than to get something. In contrast, most people with acquired deafblindness use communication for varied purposes. The enormous effort it takes for people who are deafblind and their social partners to communicate affects the variety of purposes for which communication is used (Fletcher & Guthrie, 2013). It is likely that communication remains more instrumental and less personal. Moreover, communication delays in people with congenital deafblindness, as well as the limited variation in communicative purposes, are associated with the quality of social interactions. Several studies have shown that social interactions are of poor quality for individuals with deafblindness (Correa-Torres, 2008; Lieberman & MacVicar, 2003; Prain, Ramcharan, Currie, & Reece, 2010; Vervloed, van Dijk, Knoors, & van Dijk, 2006).

Communication by Touch

If hearing and sight are missing, touch is the most appropriate sense for communication and learning. The processes of perception and learning differ across sensory modalities, however. In contrast to sight, touch operates sequentially, not simultaneously. This means that tactual information can only be gathered piece by piece and then has to be synthesized, which takes far more time than the simultaneous visual perception of a whole object or event (Bruce, 2005b). Bruce (2005a) has explained the enormous burden of dual sensory loss on information processing as the consequence of the way the world is perceived through the tactile modality. Tactile information is detailed, and building up an image on the basis of this kind of information requires a parts-to-whole approach. This is much more difficult and time consuming than the whole-to-parts approach used by most sighted people. People with well-functioning vision can see the whole picture first and can then focus on the details that interest them; people with dual sensory loss experience the world in details and have to construct the whole picture on the basis of these details.

Like the tactile sense, hearing is also dependent on sequential information, but there is a strict, systematic order of the incoming information in hearing. Sounds have to be produced in a logical order to become words and sentences, but synthesis of auditory-based language information seems to be almost automatic. Although tactual information is also received sequentially, the order in which it is gathered is normally not strict (although there are exceptions, such as in reading braille) and synthesis of that information is not automatic. Processing tactual information (for example, recognition of an object from various touches of its parts) takes more time and requires more memory capacity than would processing of an auditory-based speech signal. First of all, this has consequences for learning speed. People who are deafblind need more time for learning. According to Rødbroe and Janssen (2006), people who are deafblind also need many breaks during interactions to be able to receive, perceive, and reflect on incoming information but also to regain mental strength because information processing with limited sensory inputs is strenuous.

Some people who are deafblind cannot communicate vocally because of the hearing disorder or with sign language because of the visual disorder. As a consequence, they have to communicate with touch-based communicative forms such as tactile signing. Only people who are trained can communicate in these ways and only a few people are really fluent in these ways of communication. The communication of people with deafblindness is often understood only by people close by, such as some professionals, parents, or partners. Consequently, the number of communication partners is restricted and those partners are not always people the individual with deafblindness would have chosen themselves. In the case of children, these partners are often much older than they are which deprives them of peer interaction. Most of the time they can only interact with someone who is able to communicate by touch. Frequently, no natural context for developing communication is available (Rødbroe & Souriau, 1999).

Language and Communication Challenges and Consequences

Dual sensory loss always has a major impact on language and communication. Many people with early deafblindness fail to acquire speech. In the absence of speech and of alternatives to speech, deafblind people are likely to remain at a prelinguistic level of language development and often rely on idiosyncratic and unconventional forms of communication (Bruce, 2005a; Sigafoos et al., 2008). When children with deafblindness do not develop symbolic communication, they continue to express their intentions using presymbolic behaviors, such as body language, vocalizations, and gestures (Bruce, 2005a; Hartmann, 2012; Mar &

Sall, 1994). These forms are suited to communicate a desire for something, so-called imperative communication. This, as stated before, is often the only communicative function found in people who are congenitally deafblind who seem to lack the skills to communicate with other people for the purposes of communicative exchanges and negotiations about meanings (Rødbroe & Souriau, 1999). The latter type of communication is more advanced and referred to as "declarative communication." Supporting language and communication development in children with congenital deafblindness requires finding ways to create shared experiences and make language accessible and meaningful for the child (Ask Larsen, 2013).

In partially hearing people with vision loss, the severity of the visual impairment determines if and to what degree it is possible to compensate hearing loss by visual interaction and communication modes. This can be, for example, the use of objects of reference, visual sign language, drawings, pictograms, and lipreading. Many people with dual sensory loss, even those with functional vision and/or hearing, will need special communication support in the tactile modality. The tactile modality is often not used spontaneously and therefor needs to be trained.

Dammeyer (2014) and Nicholas (2010) have emphasized the complex relationship between limited access to the world in people with dual sensory loss, communication problems, and cognitive delay. Consider, for instance, the fragmented exposure to language people with deafblindness experience. This fragmented exposure makes it more difficult for all people with dual sensory loss to map references to the elements in the world. The consequence of their fragmented perception of the world is that they can miss information or not really grasp the meaning of what has been communicated. These problems, combined with potential sensory, language, and experience deprivation can lead to cognitive delays (Nelson, van Dijk, McDonnell, & Thomson, 2002). People who are congenitally deafblind are especially likely to have severe cognitive and intellectual delays. For a clinician, however, it is very difficult to figure out whether intellectual and cognitive disabilities are the result of deprivation and other consequences of deafblindness or are of a congenital nature and not directly a result of the sensory losses.

According to Dammeyer (2010), cognitive abilities of people who are deafblind are related to age (with older people showing reduced cognitive abilities) and communication level (with limited communication abilities associated with limited cognitive abilities). There is, however, also an interaction between communicative abilities and the partner's communicative competence; the more partners with training in deafblindness, the better the communication abilities of the person who is deafblind (Dammeyer, 2010), and the more complex the interpersonal communication (Damen, Janssen, Huisman, Ruijssenaars, & Schuengel, 2014). It is the quality and not so much the quantity of communication that seems important. This is the case, at least for children who are deaf. There is a direct and indirect association between the quality of the child's language and the occurrence of behavioral problems but not for the amount of communication (Barker et al., 2009). It seems reasonable to assume that language and communication proficiency might be equally important for the development of cognition and behavior in people who are deafblind.

Another consequence of language and communication challenges is that people who are deafblind may also have difficulty in making themselves understood. Even deafblind people who can speak may have a limited vocabulary and problems with the pronunciation of words. The latter is caused by the fact that visual imitation is used in learning the correct pronunciation of words. This was shown by Mills (1983), who found that especially sounds with a clear labial or labial-dental articulation are difficult to learn for young blind children. Many people with dual sensory loss, however, are not able to speak at all.

Consequences of Early Versus Late Deafblindness

The impact of dual sensory loss on language acquisition and communication development is different for people with acquired deafblindness than for people with congenital deafblindness. An important difference was already mentioned with regard to the functions of communication; people with congenital deafblindness often do not show other communication functions than to get something, whereas most people with acquired deafblindness also use other communicative forms (Rødbroe & Souriau, 1999). Since acquired deafblindness is a term commonly used for people for whom the dual sensory loss manifests itself after the start of language, this implies that the person has had at least some experience with the sharing of attention to elements in the environment. The experience of joint or shared

attention to an object or event (or another person) with a potential communication partner is a basic step toward communication and language development in all children (Bråten & Trevarthen, 2007; Bruce, 2005a; Eilan et al., 2005; Hartmann, 2012). Trevarthen has shown that both joint attention skills and symbolic communication are manifestations of a developing awareness of self and other, which he calls "intersubjectivity." Intersubjectivity is, according to Trevarthen, innate and develops between the age of 0 and 6 years as a result of the interplay between a child and his social partners (Trevarthen & Aitken, 2001). The impact of acquired dual sensory loss on language and communication development will be highly dependent on the amount of intersubjective development and communication experience that already has taken place. People who were able to fully develop communication abilities before they lost their hearing and sight need to learn compensatory strategies such as tactile sign language or fingerspelling, but they do not need to learn what communication is.

Consequences of Proximal Versus Distal Sensory Information Processing

Impairment in both vision and hearing can be the source of several specific challenges to learning. Although the exact nature of these difficulties is dependent on the degree of an individual's vision and hearing loss, some general trends can be identified for deafblind people. Hearing and vision are both distance senses. In contrast to touch, smell, and taste, no direct bodily contact with the source of the sensory stimulation is necessary. With intact vision and hearing, sound and visual sources can be far away and still attract attention, but this is not the case for most deafblind people. Distance from a source of sound will attenuate it significantly because sound intensity is proportional to the squared distance between source and listener. Doubling the distance, for example, reduces the volume by a factor of 4. Therefore, when hearing is limited, distance results in even greater difficulty in perceiving a sound. In the case of limited visual acuity and/or contrast sensitivity, distant objects might still be detectable but visual details are easily lost.

As a result of their limited ability to perceive distant visual and auditory stimuli, persons with deafblindness seem more oriented to their own body and to stimuli in their direct surroundings than to distant stimuli. This gives an impression of egocentrism, but it is important to remember that this "egocentrism" is not of neurological or social-emotional origin but of sensory origin. Because auditory and visual information is missed, the sphere of attention is restricted to the immediate environment and sometimes does not extend to the world outside arm's length. Such a focus on proximal rather than distal information is often reinforced by parents, professionals, or other interaction partners. For example, Preisler (1995) and Kekelis and Andersen (1984) showed that mothers of blind children tend to communicate about topics that take place here and now, that is, are present in time and place, whereas mothers of deaf children communicate about external events and objects but are less likely to communicate about feelings and thoughts (Preisler, 1995). When both senses are limited, it is understandable that topics of verbal communication change and are limited as well.

When awake, there is always something to see, since visual stimulation is omnipresent and, normally, continuously available. Auditory stimulation is less present and continuous but still more present than olfactory and tactual stimuli because the latter two have to be really nearby to smell or touch. Reduced functioning, because of vision and hearing loss, automatically leads to an overall decrease in sensory input. Sometimes this is accompanied by experiential and social deprivation as well. As a consequence, one can see a lot of withdrawn and egocentric behavior in deafblind people. To compensate for this deprivation, the individual with deafblindness often reverts to unconscious stereotyped motor behaviors (Nafstad & Rødbroe, 1999). These behaviors are very stigmatizing because they look strange and awkward and people easily assume the individual with deafblindness might be intellectually disabled as well.

Reduced visual and auditory functioning also places a restriction on spontaneous and incidental learning. Sighted and hearing children normally visually observe a lot of events going on around them and pick up a lot of verbal information that is not necessarily directed to them. They learn from what other people are doing and how other people respond to each other, not because they are instructed to do so but because they witness these situations. For a large part these spontaneous learning situations are missed by people who are deafblind. Consequently, they learn less from everyday experiences and need formal instruction on many aspects of everyday life.

Social-Emotional and Behavioral Challenges

A common finding in people who are deafblind is the high prevalence of mental and behavioral disorders. Exact rates are unknown because deafblindness is still underdiagnosed in people with intellectual and multiple disabilities (Fellinger et al., 2009; Meuwese-Jongejeugd et al., 2008). Within a group of 95 Danish people who are deafblind, Dammeyer (2011) found that 34% were intellectually disabled, 13% had a psychosis, 11% mood and affective disorders, 5% obsessive-compulsive disorder (OCD), 5% behavioral disorders (hyperkinetic and/or conduct disorders), and 4% anxiety disorders. Only 26% had no mental or behavioral disorders at all. It is important to note that there was no significant association between etiologies of deafblindness or level of vision and hearing and the occurrence of a mental or behavioral disorder. As is the case with cognitive delays, it is clinically very hard to figure out whether these disorders are the result of deafblindness per se or, indirectly, of the sensory deprivation that comes with the deafblindness, or of further effects of the cause of the deafblindness or even of side effects of medical treatments the person has undergone.

Although there is no empirical evidence that attachment disorders are more common among people who are deafblind than among other multiply impaired people or people without disabilities, there is the general belief among educators that emotional bonding between children who are deafblind and their parents is at risk (Knoors & Vervloed, 2011; Rødbroe & Janssen, 2006). In children who are either deaf (Marschark, Lang, & Albertini, 2006) or blind (Warren, 1994), no increased risk for attachment problems was found. However, the idea is that safe attachment relations are more difficult to establish if a child can neither see nor hear his or her caregivers' actions. In addition, caregivers often have difficulty interpreting the child's reactions, which are different from that of a sighted and hearing child, and subsequently have difficulty being responsive. According to McInnes and Treffey (1982), this situation can be exacerbated by hypoactive or hyperactive behaviors resulting from sensory deprivation. Both teaching and intervention programs (McInnes & Treffey, 1982; van Dijk, 1986; van Dijk & Janssen, 1993) as well as treatment of psychopathology in people with deafblindness (Sterkenburg, Schuengel, & Janssen, 2008a, 2008b; van Dijk & De Kort, 2005) commonly start with establishing an emotional bond between child and parent, teacher, or therapist.

Assessment of Language, Communication, and General Development

An integral part of the support of people with deafblindness is assessing their abilities, their strengths, and their weaknesses. Different aspects of a person's development should be assessed in order to foster language and communication in someone who is deafblind. One should find a method that the person understands (cognitive and linguistic level), perceives (sensory level), can respond to (linguistic and/or motoric level), and is in accordance with the current level of functioning and interests (personal, social, and developmental level). Therefore, commonly the following assessments are performed (cf. Damen & Worm, 2013): medical examination of auditory, visual, and motor performance; psychological assessment of cognitive functions, personality, and personal preferences and interests; and a language and communication assessment.

The function of the assessment can be to evaluate whether someone is eligible for a certain kind of care, support, or education. For this purpose formative testing with norm-oriented instruments is often required. Because so many persons with deafblindness show severe developmental delays, formative testing with norm-oriented instruments is not very helpful because this kind of testing is not action oriented; that is, it does not give directions on how and what to support. Criterion-oriented or curriculum-based instruments might be more helpful in this respect, as well as dynamic assessment procedures in which the learning potential of the individual is assessed before and after support or an intervention (Boers, Janssen, Minnaert, & Ruijssenaars, 2013). Dynamic assessment is based on the Vygotskyan idea of the zone of proximal development, the difference between what a person can do with help and his or her actual independent performance (Vygotsky, 1978). Although easier said than done, a major goal of assessment in people who are deafblind should be to look for the zone of proximal development. This will necessitate identifying exactly what kind of help or scaffolding the person needs, since the typical next step in development as described in handbooks and developmental charts often will not be automatically achieved.

Assessment Instruments

Table 22.1 lists instruments commonly used to assess children who are deafblind. Several

Table 22.1 Assessment Instruments

Instrument	Developed for Deafblind?	Domains Assessed	Age Range Targeted	Focus on Presymbolic Skills
Callier-Azusa-G (Stillman, 1978)	Yes	All domains	0–10 years	High
Callier-Azusa-H (Stillman & Battle, 1985).	Yes	Communication	0–10 years	High
Carolina Curriculum (Johnson-Martin, Attermeier, & Hacker, 1990)	No	All domains	0–3 years (Infant & Toddler edition) 2–5 years (Preschooler edition)	Low
Communication Matrix (Rowland, 2004)	Yes	Communication	All ages: only earliest stages of communication	High
Dimensions of Communication (Mar & Sal, 1999)	Yes	Communication	All ages	High
Hawaii Early Learning Profile (HELP) (Parks & Furuno, 1995)	No	All domains	0–3 years (0–3 edition)	Low
Home Talk (Design to Learn, 2014)	Yes	Communication, learning/concept development	School-age (3+)	High
Infused Skills (Hagood, 1997)	Vision impairment	Social competence, organization	Early childhood-secondary	Low
INSITE (Morgan & Watkins, 1989)	Yes	All domains	0–2 years (short version) 0–6 years (long version)	High
Oregon Project (Anderson, Boigon, Davis, & de Waard, 2007)	Vision impairment	All domains	0–6 years	Low
SIPSS/HIPSS (Rowland & Schweigert, 2002a, 2002b)	Yes	Object interaction related to cognitive and social domains	All ages	High
Vineland (Sparrow, Balla, & Cicchetti, 2005)	No	Adaptive behavior (communication, daily living skills, motor skills)	All ages	Low

From Rowland, C. (Ed.) (2009). *Assessing communication and learning in young children who are deafblind or have multiple disabilities*. Portland, OR: Oregon Health & Science University. Reprinted with permission.

instruments can also be used with older persons. Only a few of these instruments are available in languages other than English (e.g., Communication Matrix and Vineland Adaptive Behavior Scales), but most are in English and have American norms or criteria. In the case of formative testing, the lack of items and manuals in languages other than English and the lack of target group and country-specific norms is a serious problem for the reliability and validity of the assessment. If the assessment is performed for the purpose of an individual educational plan or any other kind of intervention, it is allowed to use the instruments from Table 22.1.

Assessment Approaches

The assessment of language and communication in deafblindness and services for people who are deafblind have profited very much from three related approaches: (1) the communication matrix and tangible symbol system of Rowland; (2) the child-guided approach to assessment of van Dijk; and (3) the work of the Deafblind International Communication Network on analyzing interaction and communication in dyads with deafblind people and their caregivers.

COMMUNICATION MATRIX

An easy-to-use instrument for both parents and professionals is the communication matrix (Rowland, 2004, 2013) that can be completed in print or online and is available at no charge at http://www.communicationmatrix.org. The communication matrix is an assessment tool that emphasizes the functional uses of communication in a social world. The matrix follows a sociopragmatic approach to early communication development and uses research on tangible symbol systems. It is designed to assess how an individual is communicating, with or without speech, and to provide a framework for determining logical communication goals (Rowland, 2011). Tangible symbols are "tangible" because they are permanent and can be touched or manipulated and because there is a history of correspondence between each symbol and its referent that has a perceptual basis for the individual user (Rowland & Schweigert, 2000). The communication matrix is well organized around four reasons to communicate, seven levels of communication, 24 specific messages, and nine categories of communicative behavior (Rowland, 2013). The four reasons to communicate are to refuse things, to obtain things, to engage in social interaction, and to provide or seek information. Earlier three levels of communication were described. The levels of communication in the communication matrix are an extension of these three levels and consist of preintentional behavior, intentional behavior, unconventional communication (presymbolic), conventional communication (presymbolic), concrete symbols, abstract symbols, and language. The nine categories of communicative behavior depict the form or mode of communication and vary between body movements or simple gestures and abstract symbols or formal language. The division in reasons to communicate, levels of communication, and categories is important because the level and category of communication can sometimes vary for a person between communicative reasons. For instance, by saying "eat" to make clear that you want to eat something (abstract symbol) but clinging to a parent's trousers to communicate that you want to play (unconventional communication).

The assessment with communication matrix is a rather classical way of assessing people with deafblindness in the way that it orders abilities hierarchically. For people with deafblindness who function at the more basic levels of communication, the related tangible symbol system helps the clinician to design an appropriate communication intervention plan. This makes it a very convenient and efficient instrument for clinical practice because it points to which communication level and forms can be used in the intervention.

CHILD-GUIDED ASSESSMENT

Van Dijk's work, both on assessment and on intervention, inspired nearly everyone working with people who are deafblind. Van Dijk's assessment approach has been described in print (MacFarland, 1995; Nelson et al., 2002; Nelson, Janssen, Oster, & Jayaraman, 2010; Nelson, van Dijk, Oster, & McDonnell, 2009) as well as in instructional CD-ROMs (see Nelson & van Dijk, 2002; Nelson et al., 2009). Based on theories about sensory deprivation, attachment, social learning, imitation, and neurobiology, van Dijk sketches the main challenges deafblind children meet, which were also briefly described at the beginning of this chapter. The assessment itself consists of observations of caregiver–child interactions and spontaneous unstimulated behavior and small interventions or stimulated behaviors to see if and how children perceive, learn, and interact. Next, social interaction, communication, and problem-solving skills are assessed. In a systematic way van Dijk observes the child's behavioral state, approach-avoidance

behavior, orienting response, preferred learning channel (i.e., which sense is preferred for what stimulus), memory and learning skills (e.g., reactions to familiar and novel objects, ability to learn routines, anticipate events), interaction, communication, and problem-solving skills (Nelson et al., 2002, 2009). All these observations are done in a playful way in which the child has the lead and guides the assessment. Often several people, of whom the parents are the most important, are present during an arena assessment. The child-guided approach does not make much use of norm-referenced tests or instruments and is highly dependent on the skills of the assessors. Still, colleagues of van Dijk have been able to get a sufficient degree of reliability and fidelity for their assessment approach (Nelson et al., 2010).

ANALYZING DYADS

The success of language and communication support for people with deafblindness is highly dependent on the skills of their social partners, who have a large impact on the quality of interactions of individuals with deafblindness (Janssen et al., 2003, 2006). In several studies it was shown that social partners do not naturally adapt their communication strategies to the individual support needs of individuals. Social partners of children with congenital deafblindness were found to use communication forms that were not accessible to the child (Bruce, Godbold, & Naponelli-Gold, 2004) and regularly stand outside the child's tactile reach (Vervloed et al., 2006). Goode (1994) proposed that seeing and hearing social partners need to be able to participate in a world of proximity and touch. This requires considerable skills on the part of the social partner. Research has shown, though, that it can be difficult for social partners to properly attune to the needs of people with sensory disabilities. Parents of children with limited vision can miss opportunities for sharing attention with their child, since they may not recognize when their child is attending to something. Instead of directing their gaze or face toward an object of attention, these children may show attention with their bodies (body pointing) or may freeze their body postures (Preisler, 1991, 2005). Communication can also be complicated between parents who are hearing and deaf or hard-of-hearing children. In these cases, hearing parents have been observed to use simultaneous visual communication strategies (e.g., pointing to an object at the same time as saying or signing its name), whereas the children need sequential visual information (Loots, Devisé, & Jacquet, 2005) such as directing their visual attention to an object before making the sign that refers to that object. Even trained teachers of children with deafblindness have been observed to miss communicative behaviors of the child, to use communication that is not perceivable, and to stay outside the child's tactile reach (see Bruce, 2005a; Vervloed et al., 2006).

An important achievement of the Deafblind International communication network is that they pay special attention to all the communication partners. Their work was influenced by van Dijk, but the network members extended this by adding ideas from the intersubjectivity theory of Threvarthen and Aitken (2001). This led to the creation of a theoretical framework to describe and promote language and communication in deafblind people (Janssen & Rødbroe, 2007; Rødbroe & Janssen, 2006; Souriau, Rødbroe, & Janssen, 2008, 2009). With regard to assessment, the network members emphasized the importance of analyses of video recordings of interactions happening between deafblind people and their sighted and hearing partners. Video recordings can be very helpful to analyze interactions and communication, since it is very difficult to observe interactions online and in real time, especially if the observer is also participating in the observed session. It is especially helpful that the recordings can be viewed repeatedly and in slow motion, if necessary. Furthermore, it is common in the assessment of people who are deafblind that their physical and social environments are included in the assessment. Video recordings are an easy and convenient way to make recordings in natural situations. Parents or direct care staff members can make video recordings themselves without having to bring in an unfamiliar observer. Video recordings are not only used as a means to observe children or adults who are deafblind (see Rødboe & Janssen, 2006; Preisler, 2005) but also as part of intervention programs (Damen et al., 2014; Janssen, Riksen-Walraven, & van Dijk, 2003, 2006; Janssen, Riksen-Walraven, van Dijk, Huisman, & Ruijssenaars, 2011; Martens, Janssen, Ruijssenaars, & Riksen-Walraven, 2014; Rødbroe & Souriau, 1999). In all these intervention studies interaction and/or communication between persons who are deafblind and direct care staff members are studied and promoted with the help of video recordings, either in individual or group sessions. Behaviors that are studied include, among others, *initiatives*: starting an interaction or bringing up something new as part of an answer; *confirmation*: clear acknowledgment that an initiative

has been noticed and recognized; *answers*: positive (approving) or negative (disapproving) reaction to the partner's utterance; *turn taking*, or becoming the actor, and turn giving, or allowing the other to become the actor; *attention*: focusing on the partner, the content of the interaction, or the individuals and/or objects within the interaction context*; regulation of intensity of the interaction; affective involvement*: mutual sharing of emotions; *shared experiences*, and *shared meaning*. Staff members get feedback on their behavior both from a psychologist trained in video interaction analysis and from their colleagues. Results from empirical studies show positive results for the communicative behaviors of the individual with deafblindness as well as the seeing and hearing partner (see Janssen et al., 2003, 2011; Damen, Kef, Worm, Janssen, & Schuengel, 2011; Damen et al., 2014).

Learning to Communicate

The first part of this chapter described that language and communication, as well as other domains of development, are seriously affected by deafblindness. How much depends on the severity of the sensory and additional disabilities and the age of onset of the deafblindness. After proper assessment one can formulate goals for language and communication intervention. For the intervention itself two things are important: the use of an appropriate augmented and alternative communication (AAC) system and building a communicative environment so that communication partners learn strategies to promote language and communication.

Augmented and Alternative Communication

AAC encompasses the use of unaided (e.g., gestures, manual signs) and aided (e.g., symbol-based communication boards, electronic speech-generating devices) modes of communication (Sigafoos et al., 2008). Unaided AAC options for individuals who are deafblind include the movement-based and child-guided techniques developed by van Dijk (Knoors & Vervloed, 2011; Nelson et al., 2009) and tactual reception of manual signs and fingerspelling. Aided AAC options, incorporating the use of various tactile or texture objects in tangible symbols, are often used as communication modes for individuals who are deafblind. Tangible symbols are two-dimensional (e.g., photos and picture drawings) and three-dimensional objects (also called objects of reference) used as symbols by individuals who have difficulty understanding abstract symbols such as speech, manual sign language, or other abstract symbols (Rowland & Schweigert, 2000).

COMMUNICATION MODES

Most AAC methods and techniques are not specifically designed for people who are deafblind but stem from work with people with speech and language difficulties such as autism spectrum disorder or physical, intellectual, and multiple disabilities. The mode these AAC methods use must in some way be able to compensate for the loss of vision and hearing. In most cases this means that the mode is tactile. Because not every person who is deafblind is totally blind or completely deaf, modes in which visual stimuli and sounds are used are also common. In a review of intervention studies on teaching AAC to people who are deafblind, Sigafoos et al. (2008) found 10 different AAC modes across 17 studies: manual signs, gestures, fingerspelling, printed words, communication boards with line drawings, tangible symbols, textured surfaces, micro-switches, speech-generating devices, and giving tokens to communicate a request. The most commonly used modes were tangible symbols and communication boards with line drawings. The rather wide range of modes used stems from the fact that in people who are deafblind there is a large variation in sensory capacities and motoric, linguistic, and cognitive developmental levels. As a result this determines where on the continuum from abstract to concrete and from unintentional to intentional the symbols have to be so that people who are deafblind can perceive and understand them and preferably use them actively as well.

In basic communication, nonsymbolic forms of communication are used. Within the action, touch and movement cues are used to communicate. There is no distance between the form of the symbol and the referent the symbol is referring to, in spatial, temporal, and similarity features. For instance, the movement of the spoon signals that food is provided. The child co-acts with this movement by opening his or her mouth. The idea of distancing during progression of language development comes from the work of Werner and Kaplan (1963), it and can be found in the van Dijk approach (Nelson et al., 2009), the tangible systems method (Rowland & Schweigert, 2000), in Bruce (2005a, 2005b), and the approach of Stremel and Schutz, 1995). Language development is a process of progressive distancing between self and the environment and between the environment and how it is represented in thought and actions. The more complex the communication,

Table 22.2 Expressive Communication Forms

Communication by Recognition	Contingency Communication	Instrumental Communication	Conventional Communication	Emerging Symbols (Adaptations)	Symbolic Communications
Facial expressions	Body movement	Touch person	Extend object	Complex gestures	Speech, one-word
Vocalizations	Calling attention/ micro-switch	Touch object	Simple gestures	Miniature/ associated objects	Manual sign
	Facial changes	Manipulate person	Pointing	Pictures/drawings	Nonspeech symbols
			Two-switch communication	Other tactual symbols	Electronic systems
Basic communication	→	→	→	→	Complex communication

the more distancing features become apparent. The spoon itself may represent mealtime, and later a picture of a spoon or the signed or spoken word "eat" signals feeding (Stremel & Schutz, 1995). Tables 22.2 and 22.3 depict different forms of receptive and expressive communication from basic to more complex. The model used in Table 22.2 to describe stages in expressive communication is derived from Stremel and Schutz (1995), which is similar to the models used by Bruce (2005a) and Rowland and colleagues for the communication matrix (Rowland, 2004, 2009, 2011, 2013).

As can be seen in Tables 22.2 and 22.3, aided and unaided AAC forms can be either basic or more complex. Several forms can be used concurrently but normally more complex forms take over when a child progresses in development (Stremel & Schutz, 1995). Which form an individual with deafblindness uses depends on his or her unique combination of skills and abilities. Taken together, this dismisses the often-heard myths about AAC that it is a last resort, and that it hinders speech communication. According to Romski and Sevcik (2005), it is also not true that a child needs a certain minimum age and level of cognitive development to learn to use ACC, and that there is a strict hierarchy of symbols from objects to written words that one should use in AAC.

What kind of form an individual with deafblindness will use most of the time is, however, for a large part determined by that person's developmental level and whether the deafblindness is congenital or acquired. In the case of acquired deafblindness in someone who had learned to communicate by speech or sign and to read and write in print or braille, the starting position is completely different from someone who does not understand nor

Table 22.3 Receptive Communication Forms

Natural context cues	Object cues	Gesture cues	Miniature objects	Visual sign cues
Movement cues			Associated objects	Tactual sign cues
			Pictures	Speech
			Line drawings	Written words
			Other tangible symbols	Braille
Basic communication	→	→	→	Complex communication

produce speech and is not able to read or write. The former can use communication forms that rely on the written alphabet, such as tracing, that is, writing block letters in the hand palm, manual or tactual fingerspelling (see Balder et al., 2000; Crook, Miles, & Riggio, 1999a).

TADOMA, LORM, AND TACTILE SIGNING

Several communication methods are available for people who are deafblind and can use abstract language. People who have learned sign language can learn fingerspelling in the hand and people who could read print before they became deafblind can learn tracing, which is writing block letters in the hand. Three communication methods were designed especially for deafblind people: Tadoma, Lorm, and tactile signing. The Tadoma method was designed by Sophie Alcorn (1932) and named after the first two children who were taught with this method: Winthrop "Tad" Chapman and "Oma" Simpson. A form of Tadoma was also used by Helen Keller. Tadoma is normally learned by adventitiously deafblind people and is a difficult method to learn and use; it is also not an effective method for communicating with children who are congenitally blind (Crook, Miles, & Riggio, 1999b). Tadoma is a vibrotactile method in which an individual with deafblindness places a hand on a speaker's throat, jaw, and lips to perceive breath from the nose and mouth, movement from the lips, and vibrations from the throat. The thumb touches the lips and feels the movements of the lips and the airstream coming from the mouth and nose. The difference between plosives (e.g., "b" and "p") and affricatives (e.g., "ch" and "j") can be discerned, as well as the position of the mouth while producing vowels, but only after extensive training. The fingers of the individual with deafblindness touch the lower jaw and throat of the speaker. Feeling the vibrations helps to recognize what is said. Tadoma is rarely used nowadays because much training is needed to get sufficient understanding of what a speaker says (Crook, Miles, & Riggio, 1999b). Another reason is that both the speaker and the individual with deafblindness have to accept that there is tactual contact during a conversation, which is quite uncommon in most societies and makes people feel uncomfortable. However, a small number of deafblind people successfully use Tadoma in everyday communication, some of them because they have some hearing left and use Tadoma as an addition to that (Balder, Bosman, Roets, Schermer, & Stiekema, 2000).

In contrast to Tadoma, Lorm is easier to learn. In the Lorm method, letters are spelled by tapping or stroking specific regions on the hand palm and fingers of the individual with deafblindness. The Lorm method is quick and can be learned easily, especially when one uses a Lorm glove on the hand of the individual with deafblindness which has printed instructions on it about where and how to tap and stroke. By means of modern electronic gloves it is even possible to use Lorm when there is no physical contact between the sender and the receiver or the sender does not know Lorm and types a text message on a handheld device, which in turn sends it to the mobile Lorm glove.

Tactile signing is mostly used by deaf people familiar with sign language who later became blind and were no longer able to see the manual signs. For instance, people with Usher syndrome I, who are born deaf and develop retinitis pigmentosa as teenagers, sometimes need to use tactile signs. First, as their visual field starts to deteriorate, it can help if manual signs are made in a restricted area of space just below the mouth and at eye level of the person who is deafblind so that it falls within the visual field. If visual acuity and visual field further deteriorate, tactile signing may be needed. Tactile signing uses the vocabulary of sign language as much as possible. A problem arises for signs that only differ in movement or the place on the body where they are made. In those cases, context information is important for correct understanding of the message, or the manual sign is adapted for tactile signing, for instance by making the sign on the receiver's body instead of in the space before the sender. Another problem is that in some sign languages, such as Dutch sign language, the manual signs are accompanied with nonmanual signs, that is, soundless movements of the lips. In tactile signing this component is missed. In case the nonmanual sign is the discriminating factor between two signs, one of the signs has to be adapted (Balder et al., 2000).

Building a Communicative Environment

Just providing an AAC system is not enough to ensure effective and functional use of that system (Sigafoos et al., 2008). Spontaneous use of an AAC system is rare; people who are deafblind, but also their parents or caretakers, need systematic instruction to acquire the necessary skills to use AAC for functional communication. One of the things one can do to promote communication

and language in people who are deafblind is to build an environment that encourages communication. Common elements in communicative environments are as follows: the individual with deafblindness takes the lead and guides the interaction based on personal interests, likes, and dislikes; the communication partner is responsive and nondirective; opportunities for choice making are created; and communication is integrated in daily routines and activities and is part of the educational program (Knoors & Vervloed, 2011; Nelson et al., 2002; Olson, Miles, & Riggio, 1999; Stremel & Schutz, 1995; van Dijk, 1986; van Dijk & Janssen, 1993).

In most intervention programs for congenitally deafblind people, not only skills, abilities, strengths, and weaknesses are assessed but also personal interests, likes, and dislikes. They form the starting point for a communication intervention plan (Chen & Haney, 1995; MacFarland, 1995; van Dijk & Janssen, 1993). A child-directed approach, in which an adult takes the lead and the normal developmental trajectories guide goal setting for intervention, often does not work for people who are deafblind and have severe developmental delays. In case of a child with congenital deafblindness, a parent can respond to the child's behavior at first by just imitating the child's actions. This resonance strategy makes it possible to start a turn-taking interaction in a responsive way and develops rapport and trust with the child (MacFarland, 1995). The parent can further show responsiveness by moving together with the child. In these co-active movements the parent follows literally the actions of the child's movements in a reciprocal fashion to establish a mutual sharing of action and interest. By mirroring the child's actions, the parent also shows the child that his or her actions have been noticed and understood. It is a way of replacing eye contact, nodding, or giving a vocal affirmation like "hmmm" as a sign that a child's communicative acts are perceived.

Another important strategy to promote communication is to create opportunities for choice making. Choices about what to wear, eat, drink, or play occur several times each day. In addition to their frequency, being able to make choices is also important for self-efficacy and a general feeling of being in control. Being able to make choices is thus rewarding and satisfying for the child. At the same time one reduces the chance of learned helplessness in the area of self-help skills. A simple gaze, gesture, or reaching out from the child suffices to indicate what the child chooses.

Integrating communicative actions in daily activities is another common feature of communication interventions for deafblind people. Training in naturally occurring situations that are relevant for the individual with deafblindness is seen as intrinsically more motivating than organizing distinct training sessions. The difficulty is that the number of trials per day is more limited than in well-planned training sessions, and variation in interaction partner, place, and time interferes with successful learning to communicate. That is why distinct training sessions are also performed, mostly with the help of operant conditioning procedures (Sigafoos et al., 2008). An example is a study of Bracken and Rohrer (2014) in which three deafblind adults with learning disabilities successfully increased independent requesting by using an adapted version of the Picture Exchange Communication System (PECS). The adaptations consisted of enlarging the photographs and using raised lines on swell paper (i.e., paper that "swells" along specified black/dark lines when processed in special heat processors).

A last important strategy for promoting communication is building routines and scripts. By repeating interactions over and over in the same structured way, the individual with deafblindness builds up a memory trace of the event and can anticipate what is coming. By slightly changing the routine, a parent or caretaker can invoke a novelty response or anticipatory reaction by the individual with deafblindness, which can be the start of a new interaction or conversation. By working with routines, the parent can also help the individual with deafblindness to build memory for daily activities and to understand time sequences. This process is supported with the use of schedules such as calendar, sequence or memory boxes, and a diary or memory book. Depending on the individual's preferred mode of communication, these schedules and diaries are filled with tangible objects, drawings, photos, or symbols. At the start of a day the schedules can be used to communicate the day's program or to come back on previous activities. By simply turning the symbol upside down, or by putting it in the waste basket box, the end of an activity is announced. For ease of understanding by people not familiar with the communication system of the individual with deafblindness, the symbols and objects can be accompanied with written or printed words.

Conclusions

People who are deafblind form a heterogeneous group, depending on the amount of hearing and vision loss, comorbid disabilities, and age of onset of the disabilities. Whereas congenitally deafblind children often do not reach the more complex level of symbolic communication, people who become deafblind later in life can often use communication forms derived from oral speech, sign language, print, and writing. The level of cognitive development, the degree of sensory and social deprivation, and possible existing skills in language and speech or sign language determine which teaching approach for communication is possible and warranted. Many types of augmentative and alternative communication methods can be used with people with acquired deafblindness. The tangible symbols system and the van Dijk method are more suited for children with congenital deafblindness. A more recent trend is to assess people who are deafblind together with their common interaction and communication partners, such as parents, teachers, and caretakers. Assessing and teaching only the individuals who are deafblind does not suffice, since for interaction and communication to happen one needs at least two persons. Not only the skills and abilities of the person who is deafblind but also of the hearing and sighted communication partner have to be taken into account. When necessary, which is almost always the case, training and guidance need to be given to this partner. Some form of video interaction analysis is commonly used, both for assessment as well as intervention.

After this brief overview of language and communication in people who are deafblind, we would like to suggest two topics for future research. First, research should point out ways not only to improve the efficacy but also the efficiency of interaction and communication interventions. Most intervention studies are case studies, and as a result the generalization of the results to other groups of people who are deafblind is difficult. Both assessment and training are currently intense and time consuming and involve large numbers of possible communication partners, which makes them expensive and not suited for each individual with deafblindness. Ideally one needs to know the minimum amount of training for adequate communication and interaction. A second, related, topic is a need to extend the existing interventions, which mostly include professional educators and caregivers, to parents, siblings, and other relatives. In this way people who are deafblind have the possibility of meeting and communicating with more people in an efficacious and satisfactory way. On a personal and emotional level these relatives might be far more important to them than professionals, but they usually need help to develop other, possibly more intuitive and empathic, teaching techniques.

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