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Communication & Congenital Deafblindness

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Congenital deafblindness – a unique disability

1.1 Introduction

The biggest and most important challenge that **partners** of congenitally deafblind children and adults meet, is to try to understand the nature of deafblindness. Understanding deafblindness is however a prerequisite for **co-creating** true relationships with persons with this disability. You may come to understand something from reading these booklets and other written material. Simulation exercises where you try to pretend you are deafblind yourself – blindfolded and with earplugs – might help your understanding too, even though your own experiences will still be far from the way a person born with deafblindness will experience the world.

Meeting and listening to experiences told by people who have **acquired deafblindness** will certainly add to your understanding. Your understanding will however be dependent on your readiness to observe and try to take the perspective of the congenitally deafblind person with whom you are together. That means: whenever you are interacting with him, or whenever you are observing him, when he tries to make sense of the world, ask yourself:

- Why does my deafblind partner do so and so when being with me?
- How does he try to make sense of the world, when exploring objects, spaces, other persons, and events?
- His way of acting must be meaningful to himself, but how can I try to understand why this way of being in the world makes sense to my deafblind partner?
- How can I try to support his understanding by changing my own way of being together with him?
- How can I try to adapt the physical environment so that he gets access to the world?
- How can I make the world interesting and meaningful for him?
- When I think we are communicating, how can I be sure that we actually do understand each other?

These are some of the questions that might open our minds even more. Therefore we should never stop asking ourselves these questions.

Deafblindness appears very differently in each individual depending on the impact of the sensory impairments, and on the influence that additional disabilities may play in the total picture. When residual vision and/or hearing are used in a functional way, the characteristic features of deafblindness may change. This fact can make it difficult even to recognise deafblindness in some cases. Families and professionals, who have not met many individuals with this disability, may in some cases find it difficult to recognise deafblindness. Understanding the complexity of deafblindness is, therefore, also to understand that the characteristic features of deafblindness may differ from one situation to another for each individual. These differences are caused by:

- The deafblind person himself (e.g. how he feels psychically and mentally just now, and how motivated he is),
- The environment,
- And the actual relationship that the person with deafblindness is involved in.

Because of the complexity of deafblindness and because of these personal and environmental differences, partners should therefore accept that understanding the consequences of deafblindness is an everlasting, but rewarding, journey. This long-lasting journey will hopefully not only make the seeing/hearing partners understand their deafblind partners better and better, but also add to their understanding of deafblindness in general, and even their understanding of the most essential aspects of being human.

It is extremely important to put emphasis on the individual. The disability is not as important as the individual with the disability. Recognition of his or her uniqueness is essential when deafblindness is being considered. All deafblind persons have one feature in common. They all have a combined visual and hearing impairment to such a degree that it affects all situations in life. In all other areas persons with deafblindness differ.[1] The degree of the sensory impairments will have a major impact on how deafblindness in each individual limits activities and restricts participation. So will additional disabilities such as motor problems or different degrees of functional brain disorders.[2] It is however important to keep in mind that all persons with deafblindness are human beings with the same needs as those of other human beings. That means that their needs in principle are the fundamental human needs. Their ways of learning and developing are in principle not different from those which are looked upon as fundamental for non-disabled children and adults. The challenges and the differences are however obvious when it comes to the question of how to create good conditions for learning and development when deafblindness is present.[3] These booklets will try to suggest how this universally human perspective can be integrated with the social and physical environmental adaptations needed for persons with deafblindness. These approaches should aim at making the essential relationships accessible and meaningful to each deafblind person. Being able to take the perspective of the deafblind person is however a prerequisite for making this possible.

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[1] John M. McInnes, 1999 [*See:* References, No 15]

[2] Revision of The Nordic Definition (Not published)

[3] Nafstad & Rødbroe, 1999 [*See:* References, No 17]

1.2 The personal and developmental consequences

Congenital deafblindness differs from acquired deafblindness in the way that the disability is either present at birth or the onset of deafblindness occurs before language is developed. This means that a person with congenital deafblindness will have to establish the most fundamental relationships with carepersons without or with much reduced information from vision and hearing. These two senses are not only important for establishing and developing interpersonal relationships. They are also the main motivating factors for being interested in the world and for making the world coherent and meaningful. These basic interpersonal relationships and experiences in the world are the basis for personal and communicative development (see 4).

Congenital deafblindness will first and foremost lead to problems concerning development of communication, because of the very challenging environmental modifications that are needed. The development of communication is, however, still vulnerable when we succeed in adapting the physical and the social environment. Deafblindness may not only prevent/inhibit the development of communicative competencies but even the development of social competencies. A great deal of learning for seeing/hearing children happens incidentally. Seeing/hearing children can observe and follow family members, when they act practically, when they communicate, and when they have social gatherings, because vision and hearing function. While observing the members of the family, seeing/hearing children try to make sense of what they observe from a distance. They copy and explore in play what they observed, and they try to make sense of these inputs. Their family members frequently respond to them by the gaze or the voice. Later in development seeing/hearing children learn from interacting with peers. Peer interaction is not only important for communicative development, but also for learning the social rules of togetherness and for being able to take the perspective of other persons. These experiences are only possible for persons with deafblindness to the extent that the social and the physical environment are made accessible for them by their partners. In reality this means that a lot of persons with congenital deafblindness are at risk of having little or almost no experiences of peer interaction.

Inhibition of development which is caused by a combined visual and hearing impairment may consequently lead to emotional and social disturbances. These additional consequences of deafblindness often result from the fact that the disability is not recognised and understood. This means that there is a high risk that persons that meet deafblind children and adults misinterpret their behaviour and their expressions. Their ways of exploring and expressing themselves often look very different from what we observe in usual development. Therefore there is a constant risk that these different expressions are looked upon as meaningless and deviant, and not as the natural deafblind way of expressing oneself and of making sense of the world. The consequences of visual and hearing impairment can furthermore easily be misinterpreted as social disturbances and even as autistic features. Withdrawal from social togetherness can be caused by stressful and meaningless experiences, rather than caused by the fact that the deafblind persons do not want to interact and communicate. Often deafblind persons need many breaks during the togetherness to be able to receive, perceive, and reflect on the information they get. This means longer time is needed for the process of perception and processing. Breaks may also appear because deafblind persons often need breaks to regain mental strength from the very hard sensory work that is a consequence of using limited sensory inputs. Again this may easily lead to conclusions that the deafblind person is not interested or active in the interaction. Another reason that might mislead us is that using residual senses often leads to behaviours that very much resemble social and emotional disturbances or self stimulation in persons without deafblindness. If deafblindness is not recognised and understood there is a high risk that the inborn cognitive potentials and the functional possibilities of the residual senses are not acknowledged. This means that there is a risk for not recognising the potentials of deafblind children, and even more the potentials of deafblind adults. Many deafblind adults might in addition be deprived of essential human interaction for many years. If you are seen as a person with much reduced cognitive potentials, then your partners meet you with low or no expectations. As a result the partners can create unnecessary developmental problems instead of supporting and nourishing further development. However it is also important to remember that the cognitive potentials vary within the group.

Social isolation is a serious consequence of deafblindness. For some persons it will appear when the partner is out of reach. For other persons it will not appear till the situation is complex, which is typical in communication. This is obvious when more than two persons are communicating. The conditions of the environment can also suddenly change the whole situation for a deafblind person. Maybe too many things happen at the same time, and therefore create a stressful and overwhelming situation. The deafblind person may experience the situation as frightening and meaningless, and therefore withdraws. Maybe the lighting or listening conditions are creating a situation where communication is not possible anymore. Environmental problems may therefore also lead to isolation and exclusion.

1.3 How can we actually assess the characteristic features of deafblindness?

According to a resolution made at a Nordic Conference in 1986 deafblindness causes serious problems in three main areas.[4] These areas are:

- Communication,
- Orientation in the environment,
- Information.

For persons with congenital deafblindness information first of all means access to relevant experiences in the world. These experiences are however very dependent on the partner's ability to select experiences that might be interesting for her deafblind partner. The experiences should both challenge and broaden his mind. The partner has to plan for full access to the experience, and in addition she must actively take part in the experience herself with a personal involvement. If doing so, she may inspire her deafblind partner. If this is not the case, then the world will stay out of reach and be of no interest and thereby will stay chaotic and meaningless for many persons with congenital deafblindness.

When persons with deafblindness are involved in communication, orientation and information, the characteristic features of deafblindness can be observed. The characteristics will, however, differ from person to person. If a deafblind person can use residual vision, this might make deafblindness less visible in many situations, as for example when he is moving around and exploring the world. Even much reduced vision and hearing can make a lot of difference. These reduced senses may still inspire the person to move around and to explore the world. If the person is totally blind and totally deaf he rarely pays any interest to things happening outside his own body, unless a partner is triggering his interest.

The characteristic features of deafblindness appear for all deafblind persons most clearly in well- functioning relationships with other human beings. These relationships require most of the sensory system, because they are complex, which means that many things are happening at the same time. The relationship must be well–functioning, because the deafblind person will show his best when motivated and when being with a partner that interacts on his terms. This also means that the cognitive and the sensory potentials of a person with deafblindness can be masked or repressed, if and when interaction or communication is not established or developed.

The features of deafblindness can be observed in the following way:[5]

Development of coherence and meaning in communicative relationships are dependent on the use of movement and touch (**the tactile senses**) possibly supported by the functional use of residual vision and/or

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[4] Østli, 1991 [*See:* References, No. 35]

[5] Andersen & Rødbroe, 2000 [*See:* References, No. 3]

hearing. Smell also plays a big role for many persons with deafblindness, but the functional use of smell will sometimes be difficult to observe. These near senses will be involved in sustained communicative sequences. When new functions are emerging or new signs are introduced, it will be necessary to include tactile support for most persons with congenital deafblindness, that is, if communication is to be developed according to the potentials of each individual. One of the procedures used to identify deafblindness is therefore to analyse well functioning sequences of interaction or communication in video recordings. Analysing sequences of video tapes is the most efficient way in which it is possible to assess the details needed. This often happens by watching the tape again and again, focusing on the functional use of each of the senses separately in order to be able to observe how the senses actually function together. If deafblindness is present and the partner is very close you can observe the following:

- The deafblind person will actively use touch for all functions in communication or maybe just for some of them,
- If the partner uses touch and movement as one way of interacting, communication will be sustained and more advanced.

Functional use of residual vision and hearing will very often be sporadic. The use of these senses will, as mentioned, be dependent on environmental factors, the complexity of the relationship, and the motivation and the physical and psychological conditions of each individual. This means that the functional use of vision and hearing – the distance senses – may change. This is not only the case from one situation to another, but may also happen during a short sequence of communication. The function of the tactile senses is necessary for creating coherence and meaning in experiences as well as for sustaining interaction and communication. Communicative relationships consist of many sub functions happening simultaneously. These sub functions are:

- Establishing and maintaining contact,
- Turn taking and turn giving,
- Feedback to and from the partner during the course of communication,
- Joint attention to the topic, which is the theme of the communicative sequence,
- And the communicative expressions used by the partners to exchange ideas.

Some of these sub functions it will be necessary for persons with congenital deafblindness to obtain with support by or exclusively by the tactile senses.

The following can be observed in video sequences of well functioning interaction or communication between a person with deafblindness and his partner:

- Uses of vision and hearing are brief. Sometimes these senses are functioning, sometimes they are not. In a way one might say that they are turned on and off during **the flow of interaction**. This will be even more obvious when the visual and/or hearing impairment is due to cerebral problems.
- Vision and hearing function best when supported in **synchrony** with touch and movement. Persons with sensory

integrations problems are, however, sometimes disturbed if more senses are used simultaneously.

- Very rarely residual vision and residual hearing are used at the same time.
- If vision and hearing are used at the same time you may observe frequent disruptions in the interaction. These disruptions are caused whenever the deafblind person needs to regain energy.
- One residual sense cannot compensate for the other. This means that it is not possible to support hearing by lip reading, or by reading facial expressions. The deafblind person uses all his energy for listening carefully. Furthermore restricted vision does not manage this very detailed and demanding sensory support work.

These observed realities explain why there is a high risk that a person with deafblindness gets very fragmented information. The risk of getting fragmented information is present when persons with deafblindness build up mental images and when they communicate, that is, if tactile support is not available. Therefore the tempo and the reactions during sustained interaction have to be modified to suit each individual. If this does not happen, then interaction and communication will often be disrupted.

It is often very difficult for partners to understand that the complexity of the relationship has such an important impact on the functional use of residual senses. It can thus be observed that a person with deafblindness easily picks up small but interesting items, using his vision. The same person may also easily find his way visually in a well-known environment. Yet when communicating he may, however, be very dependant on support from the tactile senses, as his vision cannot manage all the different things that happen during a communicative episode between two partners. This can be observed as difficulties in sustaining visual attention, and in shifting visual attention to and from the essential parts of a communicative episode. It may for instance be impossible to read simultaneously the emotional state of the partner as well as the signs the partner produces. Thus only one part of the communication is perceived, which makes it very difficult or impossible to follow and be active in the conversation. If tactual support is offered the deafblind person may be able to divide his attention between his partner's body/face and hands by using his own hands and eyes at the same time.

1.4 What are the prerequisites for development and learning?

The following main principles are important to consider, when we look at the services being offered to persons with congenital deafblindness:

1.4.1 The acceptance and resposibility of society to acknowledge deafblindness as a unique disability and to estabish relevant services

In 1980 The Nordic Definition of Deafblindness[6] stated that deafblindness is a unique disability and that persons with this disability need specific methods for communication and for managing daily life. This definition has inspired many countries in and outside Europe to follow the statement of a unique disability, as well as the functional view of deafblindness described in the definition. In 2004 persons within **Sense** in UK managed to pursuade the European Union accept deafblindness as a unique disability. Such official statements are important for all deafblind persons. However, there is still a long way to go for parents and professionals to get the same kind of acceptance on a national and local level in their own countries.

The need for unique services is a consequence of the impact of deafblindness. In some countries national resource centres have been established. They have the obligation to develop the specific knowledge needed, and to distribute this knowledge to families and professionals involved in the services of each deafblind person. In other countries the knowledge is more based on individuals or on one or more institutions providing services for persons with congenital deafblindness. There is a long lasting tradition of sharing knowledge and of collaborating on an international level in the deafblind field. As the knowledge of today is very detailed and directly informed by research (see 3.4) the largest problem for many parents and professionals is to gain access to that knowledge. The parents need to have access to professionals who can make the knowledge useful in practice for their deafblind child. This is not only difficult on a local basis, but also at an institutional level. It is obvious that a national resource system is important for the quality of services that each individual gets. Because of the low incidence of deafblindness, the complexity of the disability and the big differences in the population, the expertise within each country is always very vulnerable. Among professionals it is often stated that developing deafblind expertise needs at least 25 million inhabitants in the country. This is one of the reasons why the Nordic Countries (Norway, Sweden, Denmark, Finland, and Iceland) in 1980 decided to collaborate on developing expertise and on training staff in The Nordic Staff Training Centre for Deafblind Services (NUD).

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[6] NNH, 1980 [*See:* References, No. 18]

Today, expertise on deafblindness is more and more developed in international networks collaborating on specific areas in the field. This development is very much supported by technical development, which makes it easy to keep in touch at a long distance and to distribute information worldwide. The co-production of this written material is an example of a close collaboration between the Netherlands and the 5 Nordic countries, which again is based on the collaboration of The Communication Network, representing Belgium, France, Denmark, The Netherlands and Norway.

1.4.2 The knowledge of profesionals on processes of development and learning

The basis of the expertise on deafblindness is a deep and detailed knowledge of how all human beings develop and learn. Deafblind children follow the same tracks as those of seeing/hearing children when it comes to communication development. However, they often develop in slow motion and in modalities that seeing/hearing children use, but without being dependent on them. These factors are the big challenges of the field. Due to the impact of the disability, one of the most serious consequences of deafblindness is that children and adults with deafblindness get only very few experiences compared to those of hearing/seeing children. Therefore it is necessary that the experiences they get are the most essential ones for developing relationships with other persons and with the surroundings. Making priorities and making the right priorities is therefore essential in deafblind services. This means that the partners must have an overview of which experiences are the most essential ones for developing communication. They also need to know when and how these experiences should be focused at any time in the habilitation programme of each individual child or adult. We experience that networking supported by consultant services is important and necessary to enable partners to make these priorities.

1.4.3 The knowledge of professionals on deafblindness

The detailed knowledge of human development and learning must be translated into deafblindness. This means, as mentioned, that all functions in principle are established and developed in the same way as in usual development, but in other modalities and at another speed. These facts require understanding of deafblindness on a general level and specific knowledge on an individual level. As a consequence the seeing/hearing partner has to be able to recognise the function from usual development in the different expressions of each deafblind person. To recognise functions for instance means to perceive and react on active touch, when it has the same function as that of eye contact. It means too that the partner must be able to recognise the attention and the interest of the child, even when it appears bodily (in the hands, in the feet, or in the body). When noticed by the partner, the partner must be able to react adequately and immediately. This is to react to touch as she would naturally react to visual attention. Another challenge is that deafblind children develop further on their own if the interaction is motivating, joyful and accessible, just like seeing/ hearing children. This fact creates another big challenge for the partners, namely to recognise new functions or expressions that are emerging. It is very difficult, when these functions appear in different modalities and different parts of the body from what they used to observe. Even if we do see and understand what we observe, we also have to react adequately upon them, which often means in other senses than we are used to react in. In other words partners have to change not only their own behaviour, but also their own mental focus.

1.4.4 The knowledge of professionals/ families on individual assessment and intervention

Assessment on different levels is a prerequisite to being able to identify the potentials of each individual deafblind person. Assessment is an ongoing process which should be used by an interdisciplinary team of professionals and parents to collect information. The information they gain guides them in what to intervene on and in how to identify the most efficient way of doing so. It is also important to know if the cause of deafblindness is due to a specific syndrome, because this can inform us about present or coming additional impairments and characteristic features. Some of the causes of deafblindness we meet today indicate possible future degeneration in the sensory impairments or motor abilities. These present or future impairments are important to take into account, when planning an individual habilitation programme.

Partners need good medical examinations to inform us about the present status of the potentials and the limitations of vision and hearing. This information is needed when planning how to adapt both the physical and the social environment for each individual. The best possible conditions can develop the functional use of the residual senses.

Neurological information can be valuable in informing us about specific learning problems and about other disabilities that need to be taken into account when planning the focus and the strategies of intervention. Besides the medical information we need pedagogical and psychological assessment on how each of the senses actually functions in the different relationships. This means how the deafblind person uses his senses, when moving around in the environment, when exploring the world, and when interacting and communicating with his partners.

In some cases one may also need to consult the physiotherapist or persons that can identify aids that might support the functional use of vision, hearing or motor functions.

The medical and functional assessment has to be followed up frequently, as the medical aspects might change, and the functional use of the residual senses might develop over time.

In this functional assessment video recordings are important for observing in detail how each of the senses functions when the deafblind child is motivated and active.

Another part of assessment, which is essential for making priorities, is to assess the interaction/communication itself. This means to analyse video recordings of well functioning interactions between the deafblind person and his partner. What we analyse in detail is what the deafblind person masters, and what he is about to develop. The functions that are about to develop will be the future focus of intervention. All intervention strategies are aimed at changing the social and physical environmental conditions in order to meet the deafblind person on his own terms.

1.4.5 The competency of the partners

The partners of a deafblind person are the most important factor for his development and well-being. All human beings develop in relationships with other persons. For deafblind persons it is essential that they meet partners who are willing and skilled in interacting with them on their terms. In fact this means partners that are able to involve themselves personally in the relationships, and willing and able to do so in a very different way from the way they usually interact with seeing/hearing persons. Collaboration is another essential factor. The concept 'partner' includes family members, friends, and professionals; in fact all the persons directly in contact with the deafblind person.

The meetings between the deafblind person and his partners often happen in many different settings or **arenas** like kindergartens, schools, working places/activity centres, and living settings. It is extremely important that all the partners agree on the way they support the communicative development. They need to make priorities together, they need to agree on the practical way of actually reaching their priorities, and they need to evaluate their plans together to be able to decide on new intervention goals. This should be an ongoing process of collaboration. The collaboration also includes making known to one another the essential experiences that each partner shares with the deafblind person. It does not mean that all partners have to do exactly the same things and in exactly the same way, but they need to agree on the overall approach, the present focus, and the attitudes.

1.4.6 Conditions of a learning environment

Due to the impact of the dual sensory impairment most persons with deafblindness will only develop and sustain communication in one-to-one situations. It means that a high staff ratio, a process of ongoing staff development, and adaptation of the physical environment all are essential factors for partners in order for them to be able to create a positive learning environment.

All development of communication is grounded in bodily experiences. With most deafblind persons bodily experiences will be the main basis of building up concepts and thereby of developing communication. Thereby the partner must be able to take the perspective of the deafblind person when they are together, experiencing the world. Partners also need to have a constant focus on the expressions of the deafblind person, and on the meaning potentials of these expressions. A high level of communication skills in the partners is essential. They include many different ways of communication. The partner must be able to interact bodily and to master sign language to a degree, which allows signs to be introduced fluently, whenever there is a possibility to match the mind of the deafblind person with an appropriate expression. The different expressions of deafblind persons themselves that derive from bodily experiences are the fundaments for further language development. For many deafblind children and adults they will stay the most important part of their communication.

Use of touch, movement, smell and taste require not only more time, but even more physical and mental activity compared to that of using vision and hearing. The learning conditions of deafblind persons always remain difficult, because simultaneous information through the tactile senses and through vision and/or hearing either is not possible or only happens in a fragmented way. When something for example is being explored by the hands, then it is not possible for the partner to comment simultaneously on the exploration in signs, neither visually or tactually. That is one of the reasons why development often happens slowly, and functions often are established one at a time. While interacting with seeing/hearing children and even with deaf and blind children it is possible for partners to add language simultaneously, when matching the attention/thinking and the action of the child.

1.4.7 Closing remarks

Deafblindness will always lead to reduced experiences. Specific knowledge and specific skills are needed in the whole **network**[7] around a deafblind person in order to facilitate good learning conditions. All the partners in the network around a deafblind child or adult need to collaborate continuously on intervention goals.

The prerequisites of developing and learning will be further elaborated in parts 3 and 4 in this booklet.

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[7] Nafstad (Not published) [*See:* References, No. 16]