

CONGENITAL DEAF- BLINDNESS

IN LIGHT OF THE UN'S CONVENTION ON THE RIGHTS
OF PERSONS WITH DISABILITIES, ARTICLE 3



How do we ensure human rights, civil
liberties and natural dignity for people
with congenital deafblindness?

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The purpose of the (...) Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

UN Convention on the Rights of People
with Disabilities, Article 1

This means that

... the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with congenital deafblindness, and to promote respect for their inherent dignity.

Netværk Øst for praksislede

CONGENITAL DEAFBLINDNESS

WHAT DOES THAT MEAN?

Congenital deafblindness is a specific impairment characterized mainly by severe communication problems due to a combined vision and hearing impairment.

Congenital deafblindness applies to:

- People who are born with a combined vision and hearing impairment
- People who acquire a combined vision and hearing impairment before acquiring language

The manifestation of deafblindness varies with the degree of vision and hearing impairment. Persons with congenital deafblindness may:

- be completely deaf and completely blind
- be completely blind and have a hearing impairment
- be deaf and have a vision impairment
- have a combined vision and hearing impairment

Article 3

Litra a)

RESPECT FOR INHERENT DIGNITY, INDIVIDUAL AUTONOMY INCLUDING THE FREEDOM TO MAKE ONE'S OWN CHOICES, AND INDEPENDENCE OF PERSONS

Generally, deafblind people are not able to engage independently with the world around them. Their impairment means that *independence* requires the availability of a competent partner.

To take an active role in life, a congenitally deafblind person needs a partner within reach whom they can opt to involve or not to involve. This partner must have the appropriate educational tools and the right professional and personal skills.

The partner is the person's link to the outside world. Using his or her own body and based on the deafblind person's individual communication needs and preferences, the partner uses tactile means to convey the outside world: objects, information, emotions, physical environments and practical activities.

Litra b)

NON-DISCRIMINATION

All congenitally deafblind people must be offered the same opportunities. Regardless where in the country and in which municipality they live, they must have access to competent and adequate support to ensure that they are *not discriminated* against in comparison with the population in general – and in comparison with other congenitally deafblind citizens.

As the group is relatively modest in size, it has to be up to the municipalities and regions to provide services or to contribute to existing services with the necessary expertise.

Litra c)

FULL AND EFFECTIVE PARTICIPATION AND INCLUSION IN SOCIETY

People with congenital deafblindness must have access to being accompanied by a competent partner who is able to serve as a disinterested channel and conveyor of information to enable the person to participate and be included in society on his or her own terms.

To fulfil this role, the partner requires training to learn about assistive aids, tactile and bodily forms of communication and how to structure a learning environment that accommodates tactile-bodily perception.

Litra d)

RESPECT FOR DIFFERENCE AND ACCEPTANCE OF PERSONS WITH DISABILITIES AS PART OF HUMAN DIVERSITY AND HUMANITY

Congenitally deafblind people make up a diverse group. There are considerable variations in the degree of vision and hearing impairment. The same is true of any cognitive and physical challenges faced by individual deafblind persons.

With the basic foundation of knowledge and tools for dealing with deafblindness in place, this diversity is reflected in a similar degree of diversity in the educational and communication strategies and teaching styles that match individual needs and preferences.

It requires insight and experience to spot the often subtle and diminutive differences and to see and embrace them as diversity in expression and language.

Litra e)

EQUALITY OF OPPORTUNITY

All deafblind people must be offered *equal opportunities* to realize their full potential.

Regardless of age, residual vision and hearing, geographic location and any additional impairments, everyone must receive individual support with the goal of full habilitation in an effort that accommodates the dual sensory loss.

Litra f)

ACCESSIBILITY

With regard to physical accessibility, deafblind people are doubly challenged, because they cannot rely on visual or auditory symbols for wayfinding.

Most people with deafblindness have one or more additional impairments of a physical and/or cognitive nature. Therefore, deafblind people are dependent on being accompanied by a personal partner in order to get around outside the home.

This partner must be able to engage in a physically and mentally close collaboration with the deafblind person to enable him or her to acquire knowledge and information, express requests and make choices.

Litra g)

EQUALITY BETWEEN MEN AND WOMEN

The environment in which the deafblind person is, must have general knowledge about how *equality* is ensured in all relevant aspects of life.

In our assessment, there are no specific challenges relating to this section of the article in our part of the world.

Litra h)

RESPECT FOR THE EVOLVING CAPACITIES OF CHILDREN WITH DISABILITIES AND RESPECT FOR THE RIGHT OF CHILDREN WITH DISABILITIES TO PRESERVE THEIR IDENTITIES

From birth, it is important to determine the presence of any vision or hearing impairment meeting the criteria for the diagnosis of congenital deafblindness.

Children should be offered a specialized school setting that promotes learning with *respect* for their particular learning approach based on or supported by tactile means.

In youth, their engagement with the world is manifest in their bodies and minds. A targeted effort aimed at developing their tactile language will help shape their identity as persons with deafblindness. This prepares them to enter adulthood with their own, unique *identities*.

BASIC PREMISE:

SPECIALIZED SERVICES

Services for congenitally deafblind people should be specialized and should include at least a small group of deafblind people to ensure that the service provider is able to train employees and to maintain and develop the staff's professional level.

The service provider should play an active role in national knowledge sharing and professional development.

The environment around people with congenital deafblindness should be designed to accommodate individual needs. Special care must be taken in designing both the physical and social aspects of the setting to offer an optimal environment.

BASIC PREMISE:

THE COMPETENT PARTNER

A premise for the deafblind person's ability to act in and engage with the world is that the partner who acts as the person's eyes and ears has the necessary competences to offer full habilitation.

This means that the partner must possess a specific set of skills and competences to be able to convey information, knowledge, experiences and emotions by tactile-bodily means.

We have prepared a paper, accompanied by video clips, that describes the specific partner qualifications. The material presents examples of practices related directly to the individual principles in the Convention – you can find the material here:
www.dbf-konventionen.dk

BASIC PREMISE:

SPACE OF DIGNITY

A premise for complying with Article 3 of the UN's Convention on the Rights of Persons with Disabilities is that all deafblind people be granted a space of dignity based on the principle of having a competent partner available at arm's length.

This principle is centred around the deafblind person, who has to be independently able to opt to engage in contact – however, opting not to engage in contact does not constitute a waiver of the principle, merely the decision not to engage in contact for a self-determined period.

This describes the distance that is defined by the deafblind person's body, and which constitutes the boundary of the deafblind person's dignity, autonomy and independence. If we as partners step outside this space, the deafblind person loses his or her ability to interact with the outside world – and thus loses his or her access to equality.

THIS BOOKLET IS THE RESULT OF A LENGTHY PROCESS INVOLVING PROFESSIONALS FROM ALL OVER DENMARK WHO HAVE CONTRIBUTED KNOWLEDGE ABOUT THEORETICAL AND PRACTICAL ASPECTS.

IF WE HAVE CAPTURED YOUR INTEREST IN ANY WAY, OR IF YOU WOULD LIKE TO KNOW MORE ABOUT CONGENITAL DEAFBLINDNESS, YOU CAN READ MORE AT WWW.DBF-KONVENTIONEN.DK AND, NOT LEAST, SEE VIDEO CLIPS ILLUSTRATING THE SPECIAL PARTNER SKILLS REQUIRED TO WORK WITH CONGENITALLY DEAFBLIND PEOPLE.

