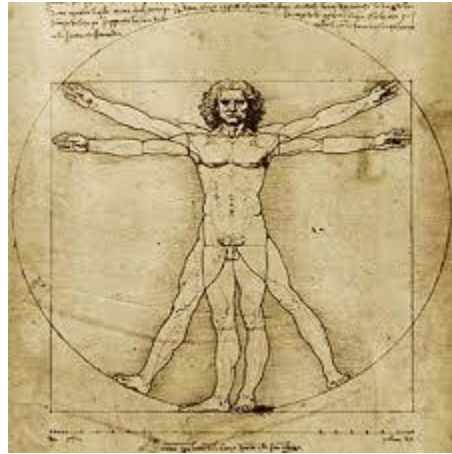
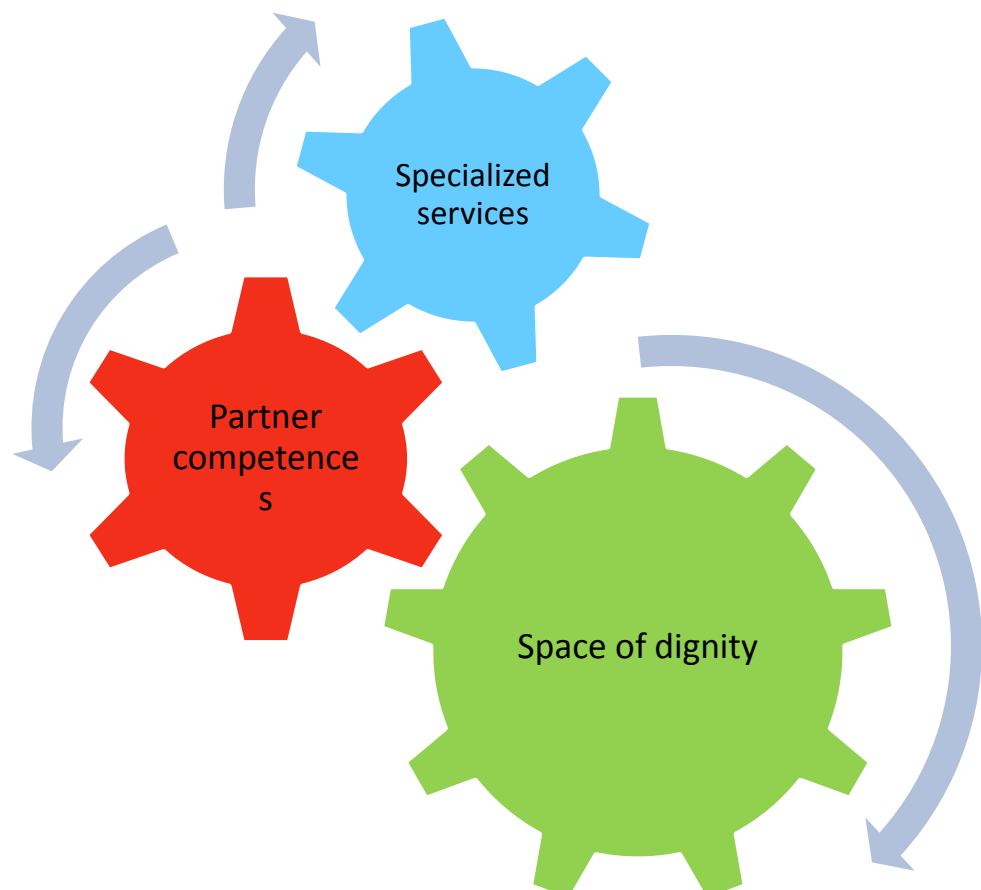


Deafblind persons' space of dignity



A description of deafblind-specific concerns in relation to the UN Convention on the Rights of Persons with Disabilities, Article 3, which specifies the general principles of the convention.



Preface

For years, as professionals working with deafblind persons we have had to explain to various cooperation partners why persons with congenital deafblindness require highly specialized services with specially trained staff and close personal contact.

We discussed this challenge at a network meeting for leaders of specialized services for persons with congenital deafblindness in spring 2013 and decided to hold a writing seminar to attempt to specify the unique conditions that pertain to our field.

The seminar had some initial problems getting off the ground, but after a few hours of debate and shared reflection, the UN Convention on the Rights of Persons with Disabilities was brought up, and we agreed to use the general principles as our point of departure in clarifying the specific conditions pertaining to persons with deafblindness – the conditions that set them apart from other disability groups.

The present paper is thus a common statement from the network of leaders of specialized residential and daytime services for persons with congenital deafblindness in Eastern Denmark.

Introduction

Congenital deafblindness is a specific functional impairment where a combined vision and hearing loss leads to severe communication problems, severe problems with accessing information and severe problems with independent orientation and mobility.

The respective degrees of vision and hearing impairment vary. Some persons with congenital deafblindness are completely deaf and completely blind, while others have some residual vision or hearing. The condition involves a dual impairment of our two most important distance senses in relation to communication.

Congenital deafblindness often coincides with other functional impairments.

The complexity of the functional impairment leads to individual requirements to the environment in the form of specialized services delivered by specially trained staff.

Deafblindness in the context of the UN Convention on the Rights of Persons with Disabilities

Based on the UN Convention on the Rights of Persons with Disabilities, Article 3: General Principles, the following is an attempt at describing the special and specific implications for persons with congenital deafblindness.

a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

Generally, persons with congenital deafblindness cannot interact independently with their environment. As a consequence of the functional impairment, *independence* requires the presence of a competent partner.

To be actors in their own life, congenitally deafblind persons need a partner within reach whom they are free to choose to involve or not. This partner needs to master appropriate educational tools and possess the right professional and personal competences.

To exercise their independence in relation to the environment, congenitally deafblind individuals depend on having a partner who can act as their eyes and ears. As a consequence of the dual sensory impairment, the congenitally deafblind person's body sets the limits for the distance to the environment.

To respect the congenitally deafblind person's inherent dignity, autonomy and independence, we have to respect the fact that the congenitally deafblind person has a space that we cannot step out of without depriving the person of her ability to interact with the environment, thus abandoning her to a sensory void.

We use the term 'space of dignity' to describe this bodily defined distance. With this term, we aim to highlight the specific aspects that characterize congenitally the living conditions of persons with congenital deafblindness.

All communication, social contact, access to information and mobility support in unfamiliar environments go through the partner. Thus, if the congenitally deafblind person does not have a competent partner within reach, she loses her dignity and stops being an equal citizen, because she has no contact with the world around her.

Due to congenitally deafblind person's communication form and learning style, acquiring new skills and activities takes time. Decoding and perception have a longer path to travel before leading to understanding, because the information goes through the body, transformed to tactile impressions. This means that time and respect go hand in hand.

The partner is the conduit to the outside world. Using her own body and based on the person's individual communication needs and preferences, the partner conveys aspects of the outside world through tactile means: objects, information, emotions, the physical environment and practical activities.

The partner has to acquire the necessary knowledge, tools and methods through appropriate training and experience in order to be able to use her own body to handle this dual communication task – from the outside world to the congenitally deafblind and from the congenitally deafblind person to the outside world.

b) Non-discrimination

All deafblind persons should have access to the same opportunities. Regardless where they live, in any municipality, they should have access to competent and adequate support without being disadvantaged, whether in comparison with the general population or in comparison to other congenitally deafblind citizens.

Geographic differences cannot be allowed to disadvantage the individual congenitally deafblind citizen in comparison with others. Since the population is relatively modest in size, it should be a municipal and regional obligation to provide specialized services or to support the existing services with the necessary expertise.

c) Full and effective participation and inclusion in society

Congenitally deafblind individuals should have the option of being accompanied by a competent partner who can serve, without self-interest, as a conduit and information provider, enabling them to take part and be included in social and community life on their own terms.

d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

Although the population is small, and all its members carry the same diagnosis, persons with congenital deafblindness make up a highly heterogeneous group. Both vision and hearing impairment vary considerably in degree. The same is true of individual cognitive challenges.

Hence, once the basic knowledge and tools for dealing with deafblindness are in place, the educational and communicative strategies and the learning styles that benefit the individual fall within a wide and diverse range.

It takes considerable insight and experience to spot the often subtle and diminutive differences and to see and acknowledge them as a diversity of expression and language characteristics. Again, this variation stems from the complexity of deafblind-specific aspects and the profound individual variations.

e) Equality of opportunity

All persons with congenital deafblindness should have equal opportunities for realizing their full potential. Regardless of age, residual vision and hearing, place of residence and any additional impairments, everyone should receive individual compensation with a view to full habilitation and with regard for the dual sensory impairment.

f) Accessibility

Accessibility in the built environment is a major challenge to persons with congenital deafblindness. Unlike many other disability groups, persons with congenital deafblindness do not have access to the full use of their distance senses – vision and hearing.

We normally rely on these senses to navigate, and persons who are congenitally deafblind thus face a dual challenge in relation to physical accessibility, because they cannot use visual or auditory cues for their navigation and orientation.

Persons with congenital deafblindness often have additional impairments such as impaired mobility and impaired cognitive capacity for transforming information and tactile signals. Hence, to be mobile, persons with congenital deafblindness need to be accompanied by a personal partner.

The near environment can be designed to include orientation and mobility features to accommodate deafblindness, but it is never going to be realistic to expect the built environment on a larger scale to be designed in a way that allows persons with congenital deafblindness to travel independently.

g) Equality between men and women

No specific relevance for the group.

h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Naturally, the points made above apply from birth. It is important to determine whether the combined vision and hearing impairment meet the diagnostic criteria for congenital deafblindness.

An especially in recent year, as the main previous cause of the diagnosis (rubella) has ceased being relevant, the young population presents with more far-reaching disorders. This is the case for several reasons, including new diagnoses, where impaired distance senses are typically a part of the overall diagnosis (e.g. Charge), new advances in the treatment of ‘weak’ infants or the simple fact that professional efforts in the field have led to increased awareness of the challenges of a combined functional impairment of our two main distance senses – including persons with multiple disabilities.

If these individuals have impaired vision and impaired hearing, however, they face particularly challenging life conditions. Therefore, they should receive qualified support and assistance to compensate for their hearing and vision loss.

They should also have access to school education in a specialized environment designed to facilitate their learning with respect for their special approach to learning or their need for tactile sensory support. In adolescence, their approach to the world manifests itself in body and mind, and in a targeted effort aimed at developing their linguistic tactility, their identity as congenitally deafblind takes shape. This prepares them to move into adulthood as bearers of their own, unique identity.

Summary – and basic premises

Basing our work on the general principles of the UN Convention on the Rights of Persons with Disabilities proved a very productive approach. It enabled us to address the conditions that have to be in place for persons with congenital deafblindness to enjoy the same rights and opportunities in life as their fellow citizens without disabilities. From a habilitation perspective, our focus has been on how to ensure that persons with congenital deafblindness can achieve equal opportunities for a life in dignity by receiving the necessary support and guidance to realize and contribute with their full potential.

In particular, we wish to highlight three basic conditions, which build on one another, and which have to be met for individuals with congenital deafblindness to become full members of Danish society:

Specialized services

The service should be specialized to accommodate persons with congenital deafblindness, and there should be at least a small group of persons with congenital deafblindness to ensure that the service is able to train the staff and maintain and develop their professional qualifications.

The service should take active part in national knowledge sharing and professional development efforts.

Partner competences

Congenitally deafblind persons' ability to act in the world requires that their partner, who acts as their eyes and ears, is competent in terms of facilitating full habilitation. There are certain specific skills and competences that the partner has to possess to be able to convey information, knowledge, experiences and emotions by tactile-bodily means.

Enclosed is an overview of the specific professional competences.

Space of dignity

Compliance with Article 3 of the UN Convention on the Rights of Persons with Disabilities requires that all persons with congenital deafblindness are granted a space of dignity based on the principle of offering access to a competent partner within arm's reach; this principle revolves around the deafblind person's own choice in making contact or not. Importantly: Choosing not to make contact does not imply a rejection of the principle but solely implies opting out of the contact for a self-determined period.

For additional information and to read more about the specific partner competences and see practice examples of the individual points described in the UN Convention, go to our website www.dbf-konventionen.dk.

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