



The Dutch Functional Definition of Deafblindness – English translation

General functional definition

A hearing and vision impairment (deafblindness) is a combined auditory and visual impairment. The degree of the hearing and vision impairments can vary and change over time. Someone with a hearing and vision impairment experiences problems with communication, and/or information acquisition and processing, and/or orientation and mobility, and/or social functioning, and/or energy homeostasis. As a result, a hearing and vision impairment hinders the performance of daily activities and participation in society. The extent of the problems someone experiences depends on an interaction between personal characteristics, environmental factors, characteristics of the combined auditory and visual functions, and additional problems. People with a hearing and vision impairment need specific care and support.

There are three subgroups: people with a congenital hearing and vision impairment, people with an acquired hearing and vision impairment, and people with an age-related hearing and vision impairment.

Congenital hearing and vision impairment

A congenital hearing *and* vision impairment (deafblindness) is a combined auditory *and* visual impairment. The auditory and visual impairment arise before language acquisition. Areas of attention for care and support for this subgroup are language and communication, orientation and mobility, and use of the residual and other senses.

Acquired hearing and vision impairment

An acquired hearing *and* vision impairment (deafblindness) is a combined auditory *and* visual impairment. The auditory and/or visual impairment arise after language acquisition. Areas of attention for care and support for this subgroup are identity development, coping with loss, self-management, and vision for the future.

Age-related hearing and vision impairment

An age-related hearing *and* vision impairment (deafblindness) is a combined auditory *and* visual impairment. The auditory and visual impairment are age-related. Areas of attention for care and support in this subgroup are remaining self-reliant, preventing social isolation, optimizing residual hearing and residual vision, and coping with loss.

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Explanation of the Dutch Functional Definition of Deafblindness – English translation

The Dutch functional definition of deafblindness and the explanation of the Dutch functional definition of deafblindness have been developed within the 'Functional definition of deafblindness' project, subsidized by Deelkracht ("Shared Force") and Kennis over Zien within the Expertisefunctie Zintuigelijk Gehandicapten (Expertise on the Sensorially Disabled) programme (ZonMw grant number Deelkracht 637003001; ZonMw grant number Kennis over Zien 637005001). Several experts with lived experience and the following organizations contributed to this project: Bartiméus, GGMD, Kalorama, Royal Kentalis, Oogvereniging ("Eye Association"), and Royal Visio.

Explanation of terminology

- The term deafblindness is used in parentheses in the functional definitions. By this, we mean that a hearing and vision impairment is also called deafblindness. There is a preference for using the combination of both terms (hearing and vision impairment, and deafblindness) in the functional definition. This has become apparent from the research prior to drawing up the functional definition.
- The term 'auditory and visual impairment' is used in the functional definitions. This does not refer to the medical meaning of the word impairment (a limitation in bodily functions and/or body structures). The terminology 'auditory and visual impairment' refers to the experience of suboptimal hearing and vision that affects daily functioning.
- In the general functional definition, the word 'problems' is used. This emphasizes that someone with a hearing and vision impairment (deafblindness) can specifically run into problems in the areas mentioned. This does not mean that every individual with a hearing and vision impairment will always experience problems in each of these areas. Moreover, the extent to which problems are experienced can change from moment to moment.
- The term 'areas of attention for care and support' is used in the functional definitions of the subgroups. This emphasizes that the areas mentioned require special attention. This does not mean that every individual belonging to this subgroup always needs care and support in each of these areas of attention or that an individual belonging to this subgroup does not also need care and support in another unspecified area of attention. A need for care or support depends on an individual's personal wishes and circumstances.
- The terms 'residual hearing', 'residual vision', 'residual senses', and 'other senses' are used in the functional definitions of the subgroups. 'Residual hearing' and 'residual vision' refer to what a person can still hear and see (respectively). 'Residual senses' are residual hearing and residual vision. 'Other senses' are touch, smell, and taste.

A medical definition

According to the Dutch medical definition, someone has a hearing and vision impairment (deafblindness) if they have an optimally corrected visual acuity of less than 0.3 and/or their visual field is less than 30 degrees, and according to an audiogram they have an average hearing loss in the best ear of at least 35 decibels at frequencies of 1000, 2000, and 4000 Hz or an average of more than 25 decibels at frequencies of 500, 1000, and 2000 Hz (the Fletcher Index) (Zorginstituut Nederland).



Describing a target group based on a medical definition is based on having an impairment in bodily functions and/or in body structures caused by illness, injury, or health problems. An impairment is defined by labelling and categorizing impairments in bodily functions and/or body structures that result in impaired functioning. According to the medical model, the problems someone experiences as a result of impairment in bodily functions and/or body structures are independent of the socio-cultural, physical, or political environment. Treatments aim to remove the cause or remedy the impairments in bodily functions and/or body structures. The medical definition does not consider the interaction of auditory and visual impairments.

A functional definition

A functional definition describes an impairment in terms of consequences for daily functioning. In a functional definition, determining whether someone has an impairment or belongs to a target group is mainly based on the obstacles that someone experiences in daily functioning, and not on impairments in bodily functions and/or body structures. A definition based on functional characteristics aligns with the philosophy of the International Classification of Functioning, Disability, and Health (hereinafter: ICF) of the World Health Organization (WHO). The ICF is 'a classification for describing the functioning of people including factors that influence that functioning'.¹ Within this classification, health is not only described from a physical point of view but also from an individual and societal perspective. The ICF emphasizes that the extent to which an impairment is experienced and there is a desire to receive support, is an interaction between personal characteristics, environmental factors, impairments in bodily functions and/or body structures, and additional problems.

Using functional and medical definition

The functional and the medical definition should always both be used to determine whether someone has a hearing and vision impairment (deafblindness). Someone who meets the functional definition belongs to the target group of people with a hearing and vision impairment (deafblindness). Someone who meets the medical definition of a hearing and vision impairment also belongs to the target group of people with a hearing and vision impairment (deafblindness). Someone with a hearing and vision impairment (deafblindness) can meet the functional definition without meeting the medical definition,² and vice versa.

Unique impairment

A hearing and vision impairment (deafblindness) is a unique impairment. The impairment is a combined auditory and visual impairment, but its implications are greater than the sum of its parts (1+1>2). After all, the senses are less able or unable to compensate for each other. Additionally, a hearing and vision impairment concerns the senses with which you can perceive from a distance (the distant senses). Observations therefore are mainly or almost exclusively possible in the vicinity. In addition to any residual hearing and residual vision, the other senses (such as touch, smell, and taste) play an important role.

Implications

Using the functional definition has several consequences. Firstly, the functional definition contributes to the acknowledgement and recognition of a hearing and vision impairment. There are people with an auditory *and* visual impairment who do not meet the medical criteria for a hearing and vision impairment but who do function as someone with this unique impairment². These people benefit from specialist support, such as education and

care, aimed at a hearing and vision impairment. Secondly, the functional definition makes clear what support may be needed for people with a hearing and vision impairment. As a result, care and services can be developed that are relevant to the specific problems that people with a hearing and vision impairment may experience in their daily functioning. Thirdly, the functional definition helps researchers in drawing up inclusion and exclusion criteria for people with a hearing and vision impairment (deafblindness) when conducting scientific research into the target group.

Abbreviated version of the general functional definition of deafblindness

When presenting the general functional definition of deafblindness in, for example, PowerPoint the abbreviated version of the general functional definition of deafblindness can be used. The abbreviated version of the general functional definition of deafblindness is <u>only</u> to be used for this purpose.

A hearing *and* vision impairment (deafblindness) is a combined auditory *and* visual impairment. The extent of these impairments can vary and change over time. Someone with a hearing and vision impairment experiences problems in various areas. This hinders the performance of daily activities and participation in society. The extent of the problems that the person experiences depends on several factors. People with a hearing and vision impairment need specific care and support.

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The information in this document is based on the research and literature research conducted within the 'Functional Definition of Deafblindness' project [Functional Definition of Deafblindness - Deelkracht].

Citations

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