

Cases about issues related to the access to Sensory Disability care and education for people with a hearing *and* vision impairment (deafblindness) in the Netherlands – English translation

Explanatory notes

The cases below deal with issues arising from a strict use of the medical definition of a hearing *and* vision impairment (deafblindness)¹ as inclusion criteria for admission to deafblind-specific care or education. The medical definition of deafblindness is based on an optimally corrected visual acuity of less than 0.3 and/or a field of vision of less than 30 degrees *and* an audiogram indicating 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 so-called Fletcher Index) ([National Health Care Institute](#)).

These cases are reported by healthcare professionals from Bartiméus, GGMD, Kalorama, Royal Kentalis and Royal Visio.

Cases

Fictitious names have been used in the cases below.

Access to care

Ms. de Groot

Ms. de Groot is a 22-year-old woman with Wolff-Hirschhorn syndrome. She is registered at the Housing department of an organisation for Sensory Disability care. She has a cerebral visual impairment, which means that visual stimuli are not passed on to or processed properly in the brain. The visual impairment arose before birth. Her visual acuity could not be measured by the ophthalmologist. Her hearing loss is 40 decibels bilaterally, making her hard-of-hearing. The hearing loss arose before language acquisition. Besides the auditory and visual impairments, she has motor impairments, a profound intellectual disability and a general sensory processing disorder. She previously attended a school for children with a hearing and vision impairment.

Why this case?

Her functioning clearly shows that Ms. de Groot has combined auditory and visual impairments that affect each other. That is also the reason why she attended a school for children with a hearing and vision impairment. However, the admission committee of the Housing department doubts whether she meets the target group criteria, since the medical definition requires an exact visual acuity score and this cannot be measured in Ms. de Groot. According to the functional definition, the patient belongs to the target group of people with a congenital hearing *and* vision impairment (deafblindness).

¹ The term deafblindness is in brackets in this document. It means that a hearing *and* vision impairment is also called deafblindness.

Ms. van Beek

Ms. van Beek is 64 years old. She has very severe hearing loss. She also has a visual impairment that has worsened significantly in a short time. She is therefore entirely dependent on tactile communication. Both her hearing loss and visual impairment arose after language acquisition. In addition to the combined sensory impairment, she is limited in her mobility: she can no longer walk long distances and can only sign for a short time. The extensive function loss of the last few years has led to an increasing need for care. She initially received support from the WMO (social support care act), but her WMO consultant indicates that with the increase in her need for care, support from the WLZ (the long-term care act) is more appropriate than the WMO. In the Netherlands, within the WLZ, we speak of hearing or visual care intensity packages. A person who has an auditory or visual impairment can receive such a package. A deafblind care intensity package, however, does not exist. Ms. Van Beek received a visual care intensity package, but that is not sufficient.

Why this case?

There is no deafblind care intensity package, only a hearing or visual care intensity package. To be eligible for a hearing or visual care intensity package, either the hearing or the visual impairment must be the primary disability. However, in a hearing *and* vision impairment, the impairments interact. The functional definition shows that for people with a hearing *and* vision impairment (deafblindness), specific care and services are required, taking into account this interaction. A deafblind care intensity package should therefore be available. Ms. Van Beek received an indication for a visual care intensity package because of her increasing visual impairment. This impairment does indeed increase the need for care, but she also has very severe hearing loss that also requires support. The functional definition takes into account the combined sensory impairment and the areas where someone experiences problems because of this impairment. Ms. van Beek belongs to the target group of people with an acquired hearing *and* vision impairment (deafblindness) and she would benefit from a deafblind care intensity package.

Mr. Vogel

Mr. Vogel is a 60-year-old man. He is registered for specialist ambulatory support at an organisation for Sensory Disability care. He has been hard-of-hearing all his life and has also acquired an eye disorder: wet (age-related) macular degeneration. His hearing loss arose before language acquisition; his visual impairment arose after language acquisition. Some years ago, he received ambulatory support for people with a visual impairment because of a lack of energy. Mr. de Vogel was successfully offered an 'activity management programme' (a method to determine the burden of daily activities). He benefited greatly from the basic strategies this programme had to offer, and from adjustments to (hearing) aids. He now also uses a white cane in the dark, which benefits him greatly. He is still working on accepting his impairments. Additionally, he is being considered for a cochlear implant.

Why this case?

Due to the use of the medical definition of deafblindness, Mr. Vogel is not eligible for specialist ambulatory support for people with a hearing *and* vision impairment, because his vision acuity is 0.5, which exceeds the criteria of 0.3. This assessment did not take into account the interaction between the visual impairment and hearing loss. The functional definition does take this into account, which means that Mr. Vogel should belong to the target group of people with an acquired hearing *and* vision impairment (deafblindness).

Mr. de Koning

Mr. de Koning is 52 years old and has a non-congenital brain injury due to an accident. Ever since, he has suffered from functional blindness, which means that he is categorised as blind based on his visual functioning. His visual impairment arose after language acquisition. In addition, he is deaf in his left ear. In his right ear he has normal hearing. His hearing loss also arose after language acquisition. Since 2019, he has been participating in rehabilitation training for people with a visual impairment at an organisation for Sensory Disability care.

Why this case?

Because Mr. de Koning has normal hearing in one ear, he does not meet the medical definition of deafblindness. However, the asymmetry between both ears combined with the functional blindness causes practical issues, for example with orientation and mobility. The limitations in activities of daily life are included in the functional definition. On that basis, Mr. de Koning belongs to the target group of people with an acquired hearing *and* vision impairment (deafblindness).

Ms. Buitendorp

Ms. Buitendorp is a 90-year-old client. As a result of her age, she has severe hearing loss. Ms. Buitendorp also has an age-related visual impairment, glaucoma. Due to the glaucoma, and due to fatigue, she has poor vision. However, the visual acuity of her best eye is 0.5, which means that her health insurance company does not consider her visually impaired.

Why this case?

Ms. Buitendorp would like to be eligible for seated patient transport. However, this is not reimbursed because, according to the health insurance company, her remaining eyesight does not meet the criteria. This decision does not reflect the fact that Ms. Buitendorp is also severely hard-of-hearing. The functional definition of deafblindness does take into account the interaction between the visual impairment and hearing loss. On that basis, Ms. Buitendorp belongs to the target group of people with an age-related hearing *and* vision impairment (deafblindness).

Access to education

Kevin

Kevin is 7 years old and has CHARGE syndrome. He attends a school for deaf and hard-of-hearing students with additional impairments (on an 'educational package for deaf children with multiple disabilities'). Kevin does not meet the medical criteria that would entitle him to an 'educational package for children with deafblindness', because his vision acuity does not fall below the criteria of 0.3. However, Kevin is hard-of-hearing and has an improperly functioning vestibular system. His visual impairment and hearing loss arose before language acquisition. He also perceives and processes sensory stimuli differently. He therefore does have a deafblind-specific support need.

Why this case?

Kevin is hard-of-hearing and despite his visual acuity of more than 0.3, he experiences serious issues with the perception of auditory and visual information from his environment. His education needs to be adapted to this. With an 'educational package for children with deafblindness', he would be able to attend a school where they take into account the interaction between the sensory impairments. According to the functional definition he would be entitled to this educational package, even though his eyesight exceeds the criteria of 0.3. The functional definition does take into account the interaction between the sensory impairments and that would make Kevin part of the target group of people with a congenital hearing *and* vision impairment (deafblindness).

Leonieke

Leonieke is 6 years old and has an intellectual disability. A request for an 'educational package for children with deafblindness' was submitted. This request was rejected on the basis of her cochlear implant (CI). Her hearing (in silence) scores at the threshold of mild hearing loss (loss of 25 decibels). Her hearing loss arose before language acquisition. Even with her CI, she has severe communication issues. Getting through the day takes Leonieke a lot of energy. That is why she is attending special education for deaf and hard-of-hearing students with additional impairments. However, due to an additional severe visual impairment, which arose before language acquisition, she cannot compensate sufficiently with her vision. This means that she has a deafblind-specific support need.



Why this case?

A school for students with a hearing and vision impairment (deafblindness) would be more suitable for Leonieke. Here, more attention is paid to her combined auditory and visual impairment through adjustments in the physical environment, adapted learning resources, more processing time, and attention to her energy level. The functional definition takes into account that vision and hearing cannot, or at least not completely, compensate for each other, and that a hearing and vision impairment is more than the sum of the individual impairments. According to the functional definition, Leonieke would belong to the target group of people with a congenital hearing *and* vision impairment (deafblindness), and thus be entitled to the 'educational package for children with deafblindness'.

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