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## **National report from Iceland 2025**

### **Sjónstöðin, National Institute for the Blind, Visually Impaired, and Deafblind**

The year 2025 was eventful, as it marked our first full year in new facilities. Sjónstöðin was awarded the title *Exemplary Institution 2024* and ranked among the top five institutions in a public sector survey assessing the work environment. The survey evaluates factors such as management, workplace morale, working conditions, flexibility, satisfaction, pride, and equality. Satisfied employees are reflected in improved services for our clients.

We have been working on fine-tuning our new medical register. According to our records, there are approximately 1,900 individuals in Iceland with visual impairment or blindness. Of these, around 200 have age-related combined vision and hearing impairment, 43 have late-onset deafblindness, and 60 have congenital deafblindness. Of 18 guide dogs working in Iceland 4 of them are allocated with deafblind individuals.

### **Survey on The Living Conditions of People with late -onset Deafblindness**

In 2025, Sjónstöðin conducted a survey among individuals in Iceland with combined vision and hearing impairment or deafblindness to better understand their situation and access to public services.

A total of 18 people participated. According to Sjónstöðin's records, 37 adults in Iceland have late-onset deafblindness.

The findings indicate a clear need for:

- Defined responsibility and improved coordination between public institutions



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- Better access to appropriate communication and information channels, including easier access to hearing aids
  - Stronger specialist knowledge and training within public systems
  - Active involvement of people with combined vision and hearing impairment in shaping the services they use

Overall, the survey shows that targeted actions, clearer government policies, and improved coordination could enhance quality of life, reduce isolation, and strengthen equality and human rights for this group.

What we aim to do with this information is to inform the Ministry of welfare of the need of better-quality service in one place for this small group of people. One suggestion is to have more services at Sjónstöðin in coherence with the wishes of the members of Fjóla.

## **Nordic Cooperation**

### **Assistance from Norway:**

Sjónstöðin received a visit from Norwegian advisors specializing in communication with individuals with congenital deafblindness, supporting a project focused on services for children.

In Iceland, there is very limited knowledge of bodily-tactile language, and there is no clearly defined responsibility for providing such services. This highlights the importance of Nordic cooperation, and the Norwegian partners responded positively to our request for support.

Staff from Sjónstöðin have participated in several working groups within NVC over the past year. Currently, staff members are involved in two networks: the Usher Network and the CHARGE Network. We also have representation in a study group on age-related



deafblindness. Additionally, two staff members enrolled in the first cohort of the Nordic Education Programme on Assessing Functional Deafblindness. This is to quality ensure the functional assessment and training as such of those performing the assessment in Iceland and of course in other Nordic countries.

### **National Cooperation**

Cooperation with Fjóla, the deafblind organization, is ongoing. Maintaining strong dialogue with its members is essential for our work. The organization has been advocating for centralized public services in one location.

Sjónstöðin has operated a functional diagnostic team since 2013, consisting of specialists from the National Hearing and Speech Institute, the Counseling and Diagnostic Center, and the Communication Center. Over time, some loss of expertise has occurred due to changes in team members and institutional management.

A significant structural change is upcoming: the National Hearing Institute will be closed and integrated into Primary Health Care of the Capital Area as of May 1, 2026. It remains unclear how this will affect our collaboration or services for the deafblind population.

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