

**Anne Gelhardt, Benno Hermes, Lisa Stockleben
Bastian Hardt, Antoinette Brücher
Anne Witte, Carolin Gravel, Nele Büchler,
Alicia Groba**

Needs and Challenges of People with Deafblindness/Hearing and Vision Impairment in Working Life

Results of the EMPLOY Project

Project Management: Thomas Kaul

University of Cologne 2025

UNIVERSITY OF COLOGNE
DEPARTMENT HEILPÄDAGOGIK AND REHABILITATION

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Foreword

The success of the EMPLOY project was only possible thanks to the openness of people with deafblindness/hearing and vision impairment to share their experiences with us. In addition, we received tremendous support from self-help associations, rehabilitation providers, integration services and counselling centres throughout the project.

Special thanks go to the team of the *Wege in den Beruf* (Paths to Employment) project at Nikolauspflege in Stuttgart. The two projects approached the topic of people with deafblindness/hearing and vision impairment in working life from two different angles, discovering many points of contact and leading to an intensive and fruitful exchange.

The same applies to the REHADAT team. Making the project results available to interested members of the public via the *REHADAT-Wissen* web platform is a sustainable solution. We would like to express our sincere gratitude to the REHADAT management and team for their invaluable support.

The project was supported by a project advisory board. Self-help associations and relevant institutions were invited to participate in the board. During the annual advisory board meetings, the current status of the project work was presented and discussed. This resulted in constructive support and the establishment of a network that helped to provide data (where available) and disseminate the study advertisement and, later, the project results. Representatives from the following associations and institutions were included on the project advisory board:

- Federal Employment Agency (Bundesagentur für Arbeit)
- Federal Working Group of Integration Offices and Main Welfare Offices (BIH) (Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen (BIH))
- Federal Working Group for the Deafblind (BAT) (Bundesarbeitsgemeinschaft der Taubblinden e.V. (BAT))
- Federal Working Group for Rehabilitation (BAR) (Bundesarbeitsgemeinschaft für Rehabilitation (BAR))
- Federal Ministry of Labour and Social Affairs (BMAS) (Bundesministerium für Arbeit und Soziales (BMAS))
- German Society for the Hearing Impaired and Professional Associations (DGHS) (Deutsche Gesellschaft der Hörbehinderten-Selbsthilfe und Fachverbände e.V.)
- German Society for Rehabilitation Sciences (AG Rehabilitation and Work) (Deutsche Gesellschaft für Rehabilitationswissenschaften e.V. (AG Rehabilitation und Arbeit))
- German Society for Deafblindness (DGfT) (Deutsche Gesellschaft für Taubblindheit (DGfT))
- Joint Expert Committee for Hearing and Visual Impairment/Deafblindness (GFTB) (Gemeinsamer Fachausschuss Hör-sehbehindert/ Taubblind (GFTB))

- Rhineland Regional Council (Inclusion Office) (Landschaftsverband Rheinland (Inklusionsamt))
- Living with Usher Syndrome e.V. (LMU) (Leben mit Usher-Syndrom e.V. (LMU))
- Heidelberg University of Education (Pädagogische Hochschule Heidelberg)
- Nikolaus Care (Institution for people with combined hearing and vision impairment: *Pathways to Employment* Project) (Nikolaus-pflege (Projekt *Wege in den Beruf*))
- PRO RETINA Germany (PRO RETINA Deutschland e.V.)
- Deafblind Service of the Protestant Church in Germany (EKD) (Taubblindendienst der evangelischen Kirche in Deutschland e.V. (EKD))

Last but not least, we would like to thank the Federal Ministry of Labour and Social Affairs (BMAS) for their financial support for the project Without this support, the project would not have been possible.

1. Introduction

Due to a variety of barriers, the opportunities for equal participation in working life are limited for people with deafblindness and combined hearing and vision impairment. Dual sensory impairment (DSI), which is defined as the impairment of both senses, hearing and vision (Bright et al., 2023), is usually a progressive condition which encompasses different stages including deafblindness. This often leads employers and medical officers to conclude that further employment is no longer possible, resulting in unwanted early retirement (cf. Kaul & Niehaus, 2013).

The EMPLOY project at the University of Cologne (running from April 2021 to July 2025) investigated challenges and conditions conducive to maintaining the employability of people with deafblindness, with DSI. It was funded by the Federal Ministry of Labour and Social Affairs (BMAS) of Germany.

The focus was on people with combined hearing and vision impairment and deafblind people who have either been deaf or hard of hearing since birth, or have been blind or visually impaired since birth, and have also experienced another sensory impairment in their lifetime. It also encompassed individuals who have acquired hearing and vision impairment during their lifetime.

This project report presents the key outcomes of the project and selected results. It also reflects on the methodological approach taken in the EMPLOY project. The project surveyed the current situation of people with DSI in working life in Germany. Based on the findings, materials were developed to address identified information gaps and limited participation opportunities: a comprehensive information brochure on deafblindness and hearing and vision impairment in working life, published in the *REHADAT-Wissen* series, and an assessment tool for identifying the participation needs of people with DSI. The concluding chapter presents further needs that emerged during the project which are essential for improving participation in working life and provides recommendations for action to address these needs.

2. People with deafblindness/hearing and vision impairment

One of the most complex disabilities that can occur alongside a hearing or vision impairment is severe dual sensory impairment, also known as deafblindness.

In cases of hearing and vision impairment, or deafblindness, the two senses that are central to perception of the environment (distance senses) are impaired. Hearing plays a vital role in language development and communication, forming an important basis for social bonds based on spoken language. Vision is of comparable importance for

coping with life. Visual perception plays a key role in acquiring information, coordinating visual perception and actions, and achieving mobility and orientation.

Vision and hearing functions do not usually occur in isolation; they are closely linked through intermodal sensory processing (Tesch-Römer & Wahl, 1996). If an impairment affects only one sense, the other sense can compensate to a certain extent, for example, when someone is deaf or has a hearing impairment and looks at the mouth of the person they are talking to. However, in cases of severe combined hearing and vision impairment or deafblindness, this compensation is limited or non-existent.

The disability profile of DSI is highly heterogeneous. Depending on when the disability begins and how severe it is, its effects can vary considerably, which has a significant impact on professional and social participation.

The following groups can be distinguished:

- People who are born with severe hearing and vision impairment or deafblindness (congenital deafblindness or deafblind since birth) or who acquire hearing and vision impairment before acquiring language;
- People who are deaf or hard of hearing from birth and acquire a vision impairment or blindness during their lifetime (e.g. Usher syndrome types I and II);
- People who are blind or vision impaired from birth and become hard of hearing or deaf during their lifetime.
- People who acquire both a vision impairment and a hearing impairment during their lifetime.

In Germany, the Joint Expert Committee on Hearing and Vision Impairment/ Deafblindness (GFTB) has formulated a more precise characterisation of the disability which differentiates deafblind people from people with combined hearing and vision impairment in various forms (DBSV 2005):

"1. People with hearing and vision impairment

a) have their visual perception impaired to such an extent that they have no vision, or their existing vision is so impaired that it can only be enhanced to a level that allows them to participate in society with the use of visually appropriate aids, and simultaneously

b) have their auditory perception impaired to such an extent that they have no hearing, or their existing hearing is so impaired that it can only be enhanced to a level that allows them to participate in with the use of suitable hearing aids, and

c) are those for whom the severity of the impairment means that natural reciprocal compensation, which can be used to participate in social life, does not take place through the remaining respective senses, but must be developed with the help of third parties.

2. Deafblind people

- a) have limited visual perception to such an extent that they have no vision, or their existing vision is so impaired that, even with the use of suitable visual aids, it cannot be increased to a level that would allow them to participate in society, and simultaneously*
- b) have limited auditory perception due to an absence of hearing or so limited hearing that, even with the use of suitable hearing aids, it cannot be increased to a level that would allow them to participate in society, and*
- c) whose natural, reciprocal compensation through sensory residues that enables participation in social life does not take place and cannot be developed”¹*

The group of people with DSI is very small: experts estimate that there are between 8,000 and 10,000 people in Germany with DSI (Kaul et al., 2014), who experience a wide range of psychosocial effects and have diverse communication needs.

Acquired deafblindness has a significant impact on participation in social life. Depending on the underlying disability — deafness or hearing impairment; blindness or vision impairment — different languages and forms of communication are preferred. Some people use sign language, while others use spoken language. For deaf people who become deafblind later in life, communication is usually most reliable in German Sign Language. For most hard of hearing, blind and vision impaired people, however, spoken language remains the preferred language.

Forms of communication range from the use of German tactile sign language and hand sign systems such as Lormen, to spoken language and written language. Written forms of communication include Braille for tactile perception and enlarged black print for those with some residual vision. The form used varies depending on the individual needs, preferences and the situation/context.

3. Project overview

The central goal of the EMPLOY project was to investigate the conditions for self-determined participation of people with DSI in working life, with a focus on the primary labour market, and to develop possible solutions. The study included all groups involved in the process of participating in working life:

1. People with hearing and vision impairment and deafblindness in different degrees including representatives of self-help associations
2. The specialist advisors and assessors involved from rehabilitation providers, e.g. the Employment Agency and integration/inclusion offices, as well as their specialist services, such as integration services and technical services²
3. The respective working environment, e.g. employers and colleagues

¹ Translated by the authors

² For reasons of better readability, they are referred to as specialist consultants in the following.

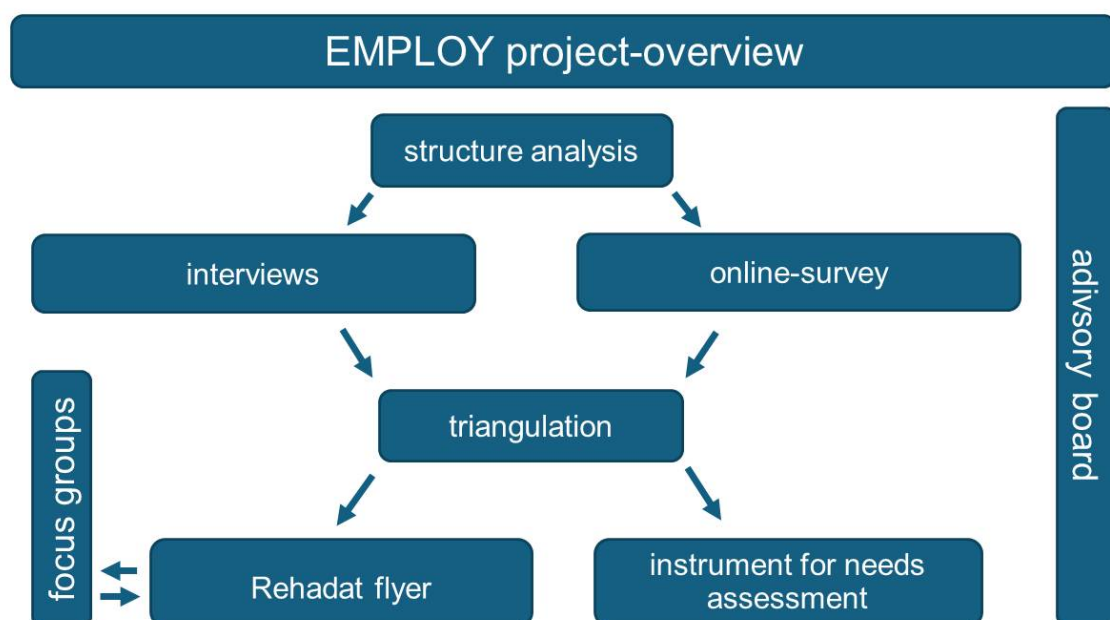
Project structure

The project was based on a participatory approach both within the project team and throughout the project activities. The **project team** included people with and without hearing or vision impairment. All relevant groups of involved people in the process of participation in working life were informed about the project and invited to exchange ideas. Representatives of self-help associations participated as members of the project advisory board. In addition, focus groups were held to discuss the project results with the groups involved and gather suggestions for further activities.

Key areas of focus

In order to be able to make statements about needs and recommendations for improving participation, the current situation of people with DSI in working life was investigated:

- First, structures were identified: Who does what in the context of *working life for people with deafblindness/ hearing and visual impairment*? What counselling and support measures are available? What structures are currently lacking?
- Based on this, a quantitative survey and a qualitative interview study investigated: What constitutes good working conditions for people with DSI? Where are barriers, challenges and limitations? Which groups of people need what information and services?



Project overview EMPLOY

Based on the results, materials were developed and distributed to improve opportunities for participation in working life:

- Information material
- An assessment tool for determining individual participation needs

4 Analysis of the current situation

The first phase of the project focused on analysing the current landscape of services for people with DSI in Germany. This was followed by the collection of data via a standardised online survey and guided interviews. The target groups for our data collection were: 1) people with hearing and vision impairment or deafblindness, 2) specialist advisors in the context of working life, and 3) people from the working environment (e.g. supervisors, employers or colleagues). The aim was to gain differentiated insights into the workplace situation.

4.1 Standardised online survey

Method

A standardised online questionnaire was developed to identify the needs, barriers and conditions conducive to professional participation of the target group. As no suitable tool for assessing the target group was available, the questionnaire was created as part of the project. Depending on their group, participants completed different survey paths with specific content. In addition to demographic data and information on forms of communication, workplace conditions, counselling and support services, retirement, barriers and information needs were also surveyed.

The survey addressed group one, which comprised people who were employed or previously employed in the general labour market at the time of study participation. Specialist advisors were addressed regarding their experiences in the consultation of people with DSI (group two) as well as people from the work environment who reported on current or past cooperation with people with DSI (group three). The minimum age for participation in all three groups was 18 years.

The survey was conducted via the online platform LimeSurvey (LimeSurvey GmbH, Hamburg, Germany). In terms of accessibility, the interface was designed so that participants could choose one of four display options at the beginning of the survey.

- (1) Text display with dark font on a light background;
- (2) text with a light font on a dark background;

- (3) a survey with sign language videos and dark text on a light background; and
- (4) a survey with sign language videos and light-coloured text on a dark background.

In the video versions, all questions, instructions and answer options were presented in German Sign Language (DGS). Deaf sign language interpreters were commissioned to produce the videos and worked with the project team to translate the content into DGS. When recording the survey videos, the interpreters wore dark clothing to create a high contrast between their clothing, hands and faces. They also made sure to sign in the centre of the image/screen to accommodate people with a restricted field of vision.

The online survey was completed using a computer mouse and keyboard. Participation was anonymous, voluntary and open to the public. Technical or content-related questions could be addressed directly to the project team.

Sample

The total sample comprised 94 participants: 51 people with DSI, 28 specialist advisors, and 15 individuals from the working environment. Figure 3.1 shows the survey sample by group. Brief descriptions of the groups are provided below.

People with hearing and vision impairment/ deafblindness (51 people)

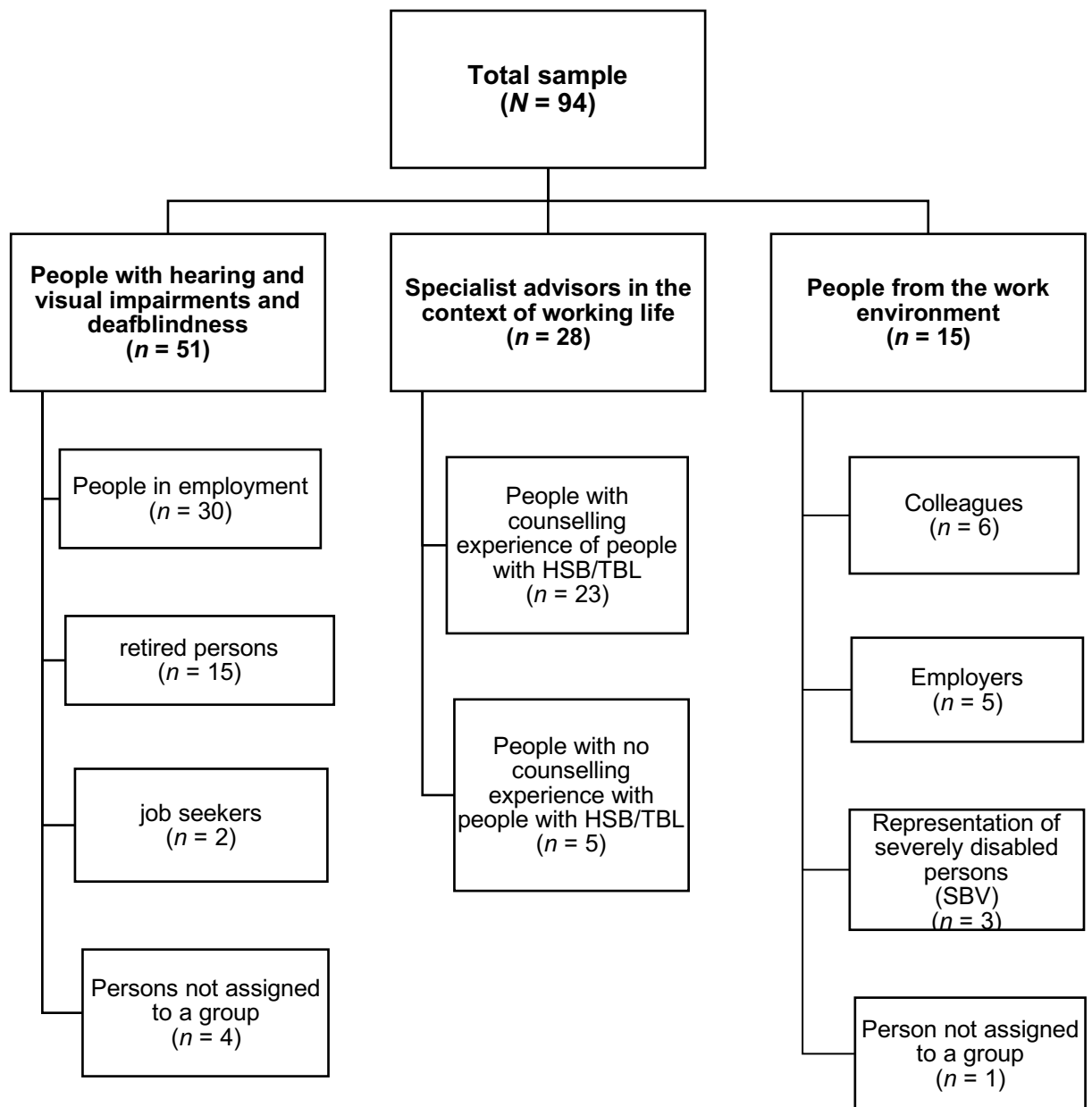
- Average age at entry into employment: 22 years (age range: 15–30 years)
- 11 federal states of Germany represented
- 38 use spoken language (74.5%), 11 use sign language (21.6%), two persons did not specify
- 3 persons in retirement pension, 12 in full disability pension, where the average age of entry was 46 years (age range: 27–59 years)

Specialist advisors in working life (28 persons)

- 2 persons deaf, 3 deafblind or hearing and visually impaired
- 11 with specific services for the target group
- 7 federal states of Germany represented
- 17 use DGS in counselling
- 14 work for the Integration Services (IFD)

People from the work environment (15 people)

- 6 federal states of Germany represented
- 9 people use spoken language, 4 use sign language, 2 use interpreters or assistants
- 8 people obtained information about the topic privately, 7 had previous experience



Total sample of the EMPLOY online survey

4.2 Interviews

Method

In the guided interviews, the three target groups were asked about the professional participation experiences of people with hearing and vision impairment and deafblindness. The focus was mainly on the challenges encountered in working life, the barriers

faced, the solutions implemented, the counselling and support provided, and the needs and potential for improvement. Interviews with people with DSI were conducted by EMPLOY project staff who have sensory impairments themselves. The interviews were carried out in the language preferred by the interviewees: either German or German Sign Language. The general points to consider were agreed individually in advance. For example, one interview was conducted using tactile sign language. Interviews conducted in spoken language were recorded, transcribed and anonymised. The sign language interviews were recorded with two cameras, translated and transcribed, and also anonymised in written form.

Sample

A total of 36 people took part in the interviews: 24 people with hearing and visual impairments and deafblindness and representatives of self-help associations, and 12 specialist advisors. Despite multiple requests and efforts to recruit people from the working environment, it was not possible to conduct interviews with this group. Their perspectives were therefore drawn from the online survey and comments made by other target groups.

People with hearing and vision impairment/ deafblindness (24 people)

- 12 people who use spoken language, 12 people who use sign language
- 6 federal states of Germany represented (including 14 people from North Rhine-Westphalia)
- 16 employed, 1 self-employed, 6 retired (5 full, 1 partial disability pension), 1 unemployed

Specialist advisors in working life (12 people)

- 2 people who are deaf themselves
- 4 federal states of Germany represented
- 8 working at the IFD, 2 in an EUTB, 1 each at the Employment Agency and the Pension Insurance Fund

4.3 Evaluation

The data from the online survey were processed using IBM SPSS Statistics (version 28). Qualitative content analysis according to Kuckartz (2018), using ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, 2023), was applied to the interview analysis. The results of the survey and the interviews were then triangulated to derive key findings for the next phase of the project. The core topics and needs were summarised systematically for each target group and will be presented and discussed in Chapter 5 below.

4.4 Challenges and reflection

The project team faced a number of conceptual and practical challenges when conducting the surveys, which are described and reflected upon below.

One of the key challenges was **recruiting participants**. Those with hearing and vision impairment and deafblindness, who are (or have been) active in the general labour market are few in number and difficult to reach. Even specialist advisors rarely come into contact with them. Recruitment therefore took place in several waves via digital channels, including social media posts, email distribution lists of project partners and specialist agencies, and links on the project website. Support from self-help networks and interest groups was particularly important. Despite the difficulty of reaching the target groups, a total of 130 people were recruited. Considering the small size of the target groups and the challenges associated with participating in surveys and interviews, this level of participation is high. However, recruitment and data collection took longer than planned. To create a sufficient sample size and ensure adequate data distribution and diversity, the survey period was extended.

Another challenge was designing the **survey instruments** to be as **accessible** as possible. The target group has diverse communication needs, technical requirements and access needs. Therefore, it was necessary to anticipate and account for a wide range of potential needs and adaptations. This affected the visual design (e.g. font size, contrast and structure), the linguistic design (e.g. clear and understandable wording) and the integration of sign language videos. However, there were limitations to the extent to which individual needs could be accommodated, as many technical barriers (e.g. screen readability, individual assistance software) lie with the users and cannot be controlled centrally. Nevertheless, four accessible versions of the online survey and interviews conducted in spoken language and sign language were created to provide many access options.

As previously mentioned, the project was aimed at a relatively small, highly connected target group. Against this background, protecting personal data was particularly important in order to guarantee the participants' anonymity and protect their personal rights. No specific information, such as job titles, was published, and any personal details, such as names and locations, were removed from the quotes from the interviews that can be found in this project report.

The project has demonstrated that successful research can be conducted with this particular target group. The number of participants and the candidness of the comments made during the interviews highlight the importance of the topic for those involved.

Close cooperation with self-help associations, rehabilitation providers and integration offices were essential for gaining access to the field.

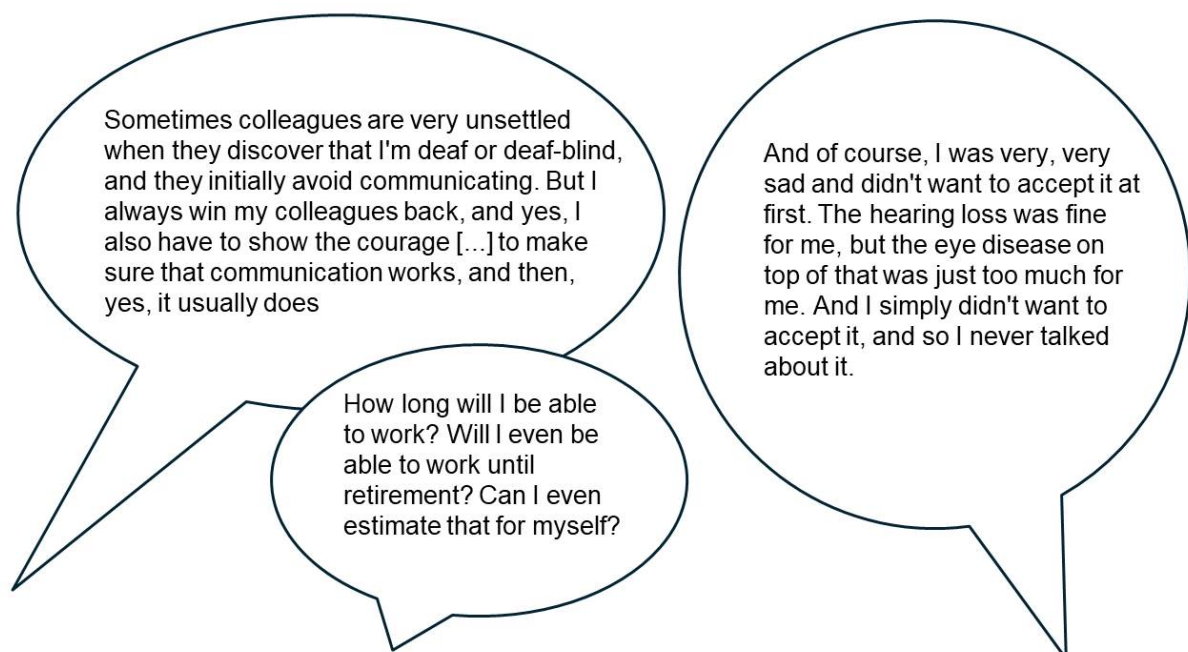
To take into account the diverse needs of all target groups, an iterative approach was adopted: the project team developed drafts which were then revised together with the target groups in several iterations. As requirements for accessibility vary greatly from person to person, it was crucial to consult the target groups in various ways, taking into account their experiences and needs.

5. Key issues, experiences and needs of people with deafblindness/hearing and vision impairment in working life

The aspects presented below are a selection from the triangulated study results, which are fully incorporated into the information brochure and the assessment tool for determining participation needs. This report illustrates key aspects with quotes.

→ Dealing with and managing dual sensory loss

Dealing with the effects of the disability is a major topic. After diagnosis or deterioration in hearing or vision, feelings of grief and loneliness are described, as well as the struggle to accept changes in perception.



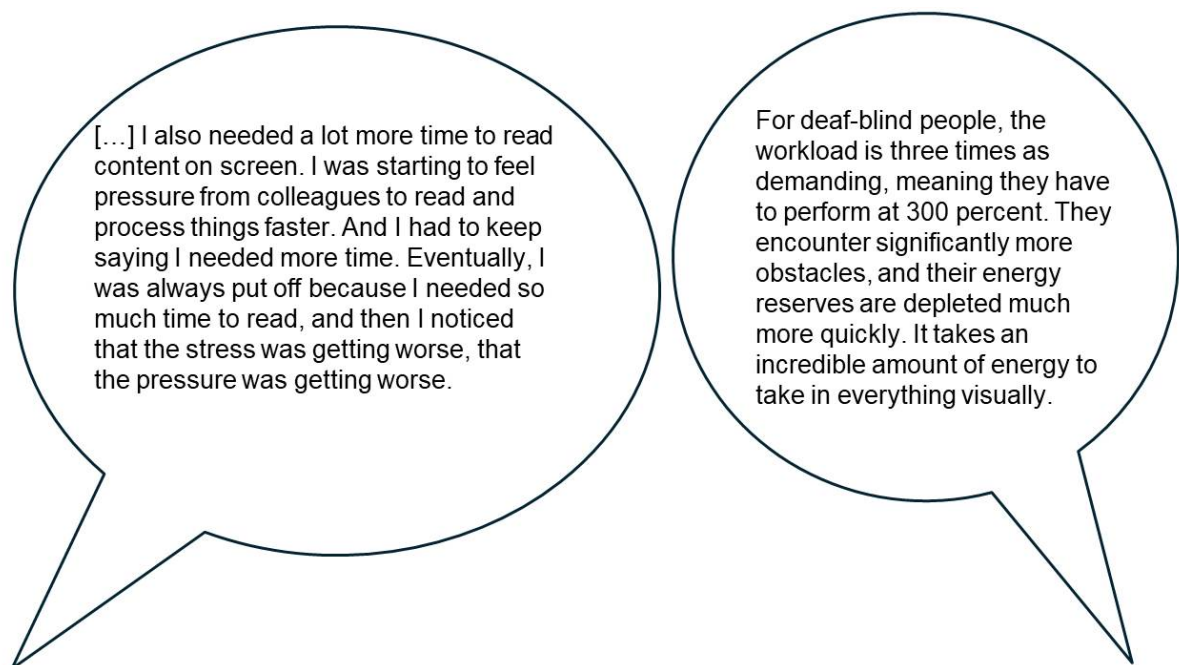
Quotes from people with DSI (source: EMPLOY interviews, 2023)

Uncertainty about the future and one's ability to work can raise many questions and cause existential fears. In this context, the lack of informational materials and com-

petent personalised advice is particularly notable. It is of significant importance to consider how openly one can address the dual sensory impairment and potential deterioration in the workplace. According to some respondents, taking a proactive approach can help alleviate colleagues' reservations, even if it sometimes requires considerable effort. Overall, there is a clear need for peer exchange, advice and support.

→ High mental and physical stress

It has been experienced by many of the study's informants that their workload capacity is limited, that tasks take longer and require significantly more concentration. This can lead to exhaustion and health problems. As colleagues do not readily associate the additional time required with deafblindness or hearing and visual impairment, people with DSI report high stress levels and feeling under pressure.



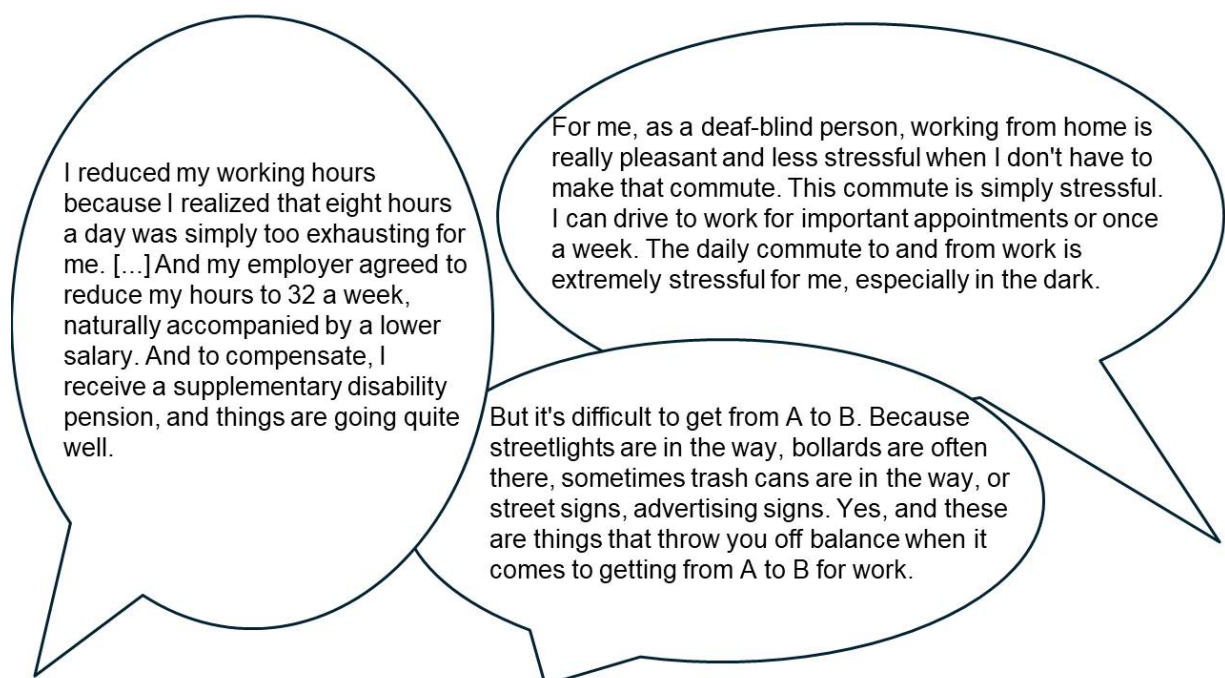
Quote from a person with DSI (left) and a specialist advisor (right) (source: EMPLOY interviews, 2023)

Specialist advisors reported that people with DSI experienced high levels of stress in their working lives. The high level of concentration required due to limited perception often leads to feelings of being overwhelmed and under pressure. This can impact the physical and mental well-being of people with DSI. There is clearly a need for services to provide relief and teach coping strategies for dealing with the altered perception and associated stress. Expert (peer) counselling and exchanges with others who have deafblindness or hearing and vision impairment (e.g. in self-help groups) are considered very helpful in this regard. Training courses on how to manage resources and limitations are also considered useful. The workplace can contribute to alleviating mental and

physical stress. Therefore, efforts should be made to raise awareness of this issue in the workplace.

→ **Helpful: flexibility in work design**

The ability to adapt working conditions and activities to individual needs was consistently identified as a key factor in promoting employability and well-being at work. In particular, flexible working models such as flexitime and flexible break arrangements were mentioned. In some cases, reducing working hours can also provide relief. One option to compensate financially is a partial disability pension, a possibility for compensating reduced earning capacities in Germany.



Quotes from people with DSI (source: EMPLOY interviews, 2023)

Working from home is another possible adaptation that can offer specific advantages to people with deafblindness/hearing and vision impairment. Long and stressful commutes are no longer necessary, which can reduce physical and emotional stress. However, it should be noted that the home office must be equipped with the necessary aids. One example is online meetings. Whether online meetings are a suitable form of teamwork for people with DSI must always be determined on an individual basis and cannot be generalised.

The impact of possible adaptations to the workplace and working conditions should not be underestimated. Challenges on the way to work are a frequently mentioned issue. Whether difficulties with regard to the commute can be resolved may determine whether a person is able to continue working or not.

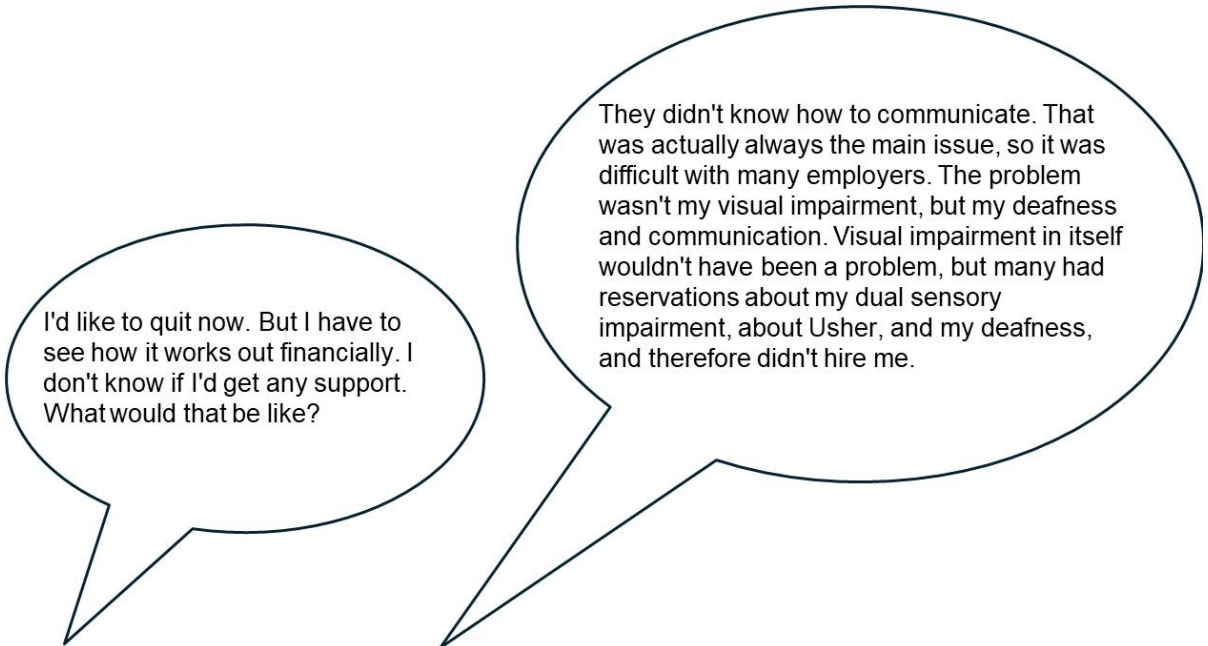
→ Lack of information

Information deficits were evident at various levels among all groups involved in the employment of people with DSI.

People with deafblindness/hearing and vision impairment require comprehensive information to enable them to make informed decisions and adapt their employment to their needs. The following topics were mentioned:

What support measures are available to me?

- What aids are available and which ones are suitable for me at my workplace?
- How do I interact with colleagues and superiors?
- Where can I find expert advice, e.g. on benefits for participation in working life, or peer counselling?
- If I am no longer able to continue working or it becomes too stressful: What financial support options are available? What about disability pension? How do I apply?



I'd like to quit now. But I have to see how it works out financially. I don't know if I'd get any support. What would that be like?

They didn't know how to communicate. That was actually always the main issue, so it was difficult with many employers. The problem wasn't my visual impairment, but my deafness and communication. Visual impairment in itself wouldn't have been a problem, but many had reservations about my dual sensory impairment, about Usher, and my deafness, and therefore didn't hire me.

Quotes from people with DSI (source: EMPLOY interviews, 2023)

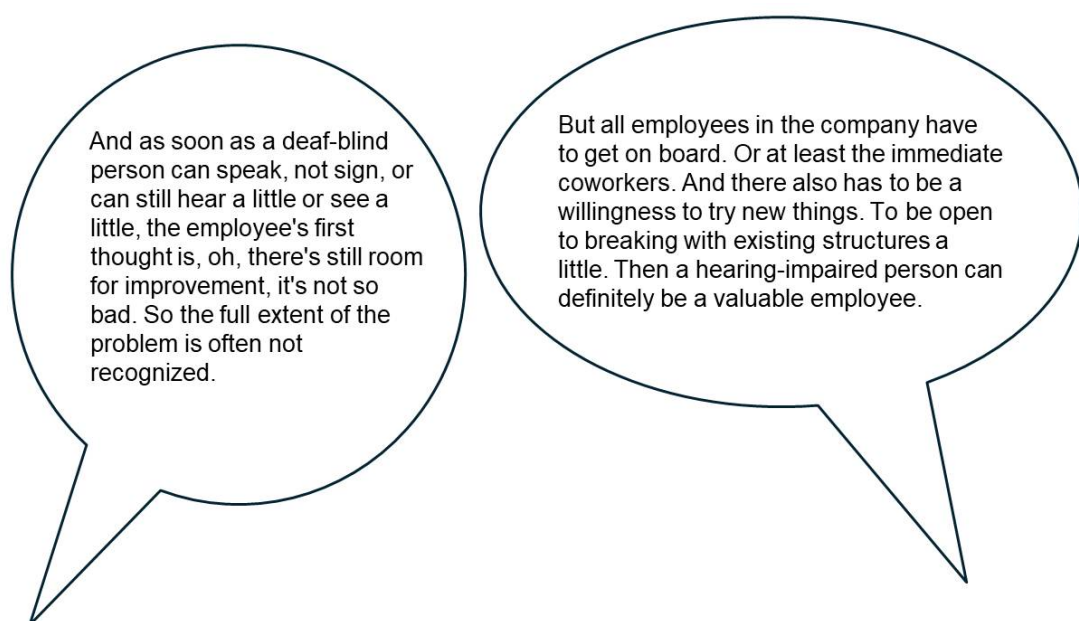
Support from colleagues, supervisors and company contact persons in the respective work environment is considered an important resource. In professional environments, there is often a lack of knowledge about the effects of hearing and visual impairment or deafblindness, and little experience of working with people with DSI. This often leads to insecurity in interaction, which can be challenging to navigate. Communication difficulties are particularly challenging in this context. For example, a colleague with DSI may not respond to a greeting during a face-to-face encounter, which is usually not due to rudeness, but rather because the greeting was not seen and heard.

In order to better understand and classify behaviours and requirements for organising work when dealing with people with DSI, it is essential to have information about the effects of dual sensory impairment.

The following questions were of particular interest to **people in the workplace**:

- How can I communicate with my colleagues with DSI?
- What financial and technical support options are available? Who can advise us?

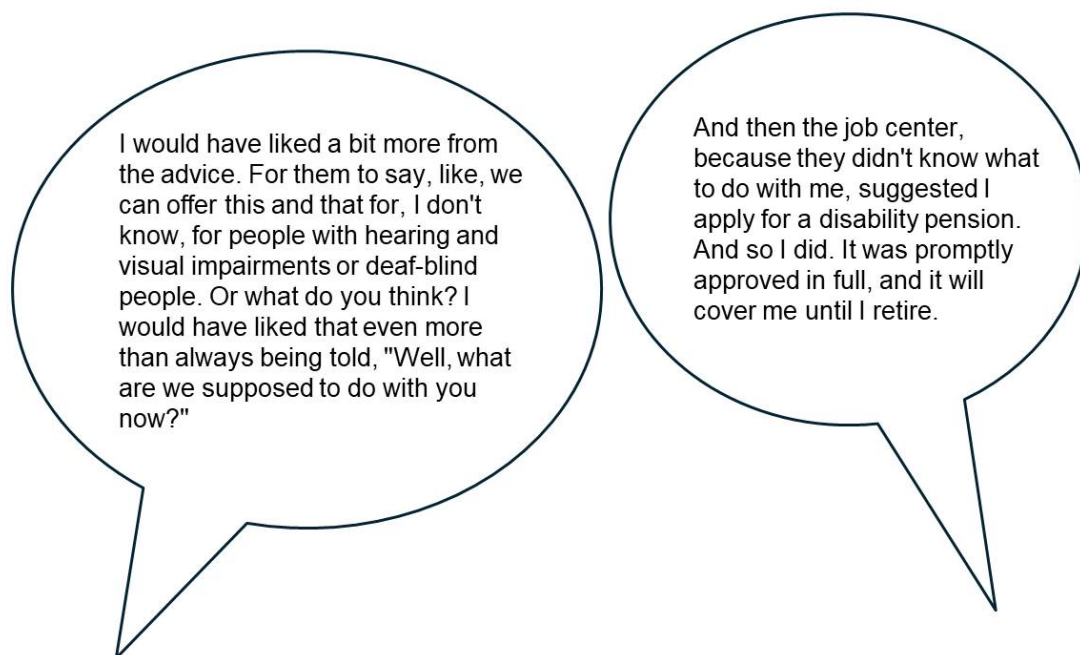
From the perspective of specialist advisors, having direct contact persons for employees with DSI in the workplace is considered an important factor in helping these employees remain in work. It is essential that people in professional environments have background knowledge about the effects of hearing and visual impairment, and feel confident when dealing with colleagues with deafblindness/hearing and vision impairment. Therefore, specialist advisors consider raising awareness in the workplace about the situation of colleagues with dual sensory impairment to be of central importance. A lack of such information can lead to communication problems and an increasingly isolated work situation.



Quotes from expert advisors (source: EMPLOY interviews, 2023)

A basic understanding among colleagues is also an important prerequisite for their willingness to support necessary workplace measures or adjustments to the work situation. It is therefore necessary to raise awareness among colleagues. Training and further education that allows for self-experience are generally considered useful for this purpose, allowing self-experience is of great importance here.

To provide expert advice, specialist advisors and assessors from rehabilitation providers, integration/inclusion offices, and their specialist services require in-depth knowledge of deafblindness and hearing and vision impairment, as well as the relevant communication skills. A variety of personal and technical aids can support individuals in the workplace, provided they are tailored to their specific needs and requirements. However, competent expert advice requires knowledge of the impact of dual sensory impairment in order to assess whether voice output, for example, is suitable for an individual with hearing and vision impairment, taking their individual hearing loss into account. However, employees with DSI included in our study report hardly any advisors with the relevant knowledge. Consequently, advice on suitable aids, measures and possible career prospects is perceived as unsatisfactory.



Quotes from people with DSI (source: EMPLOY interviews, 2023)

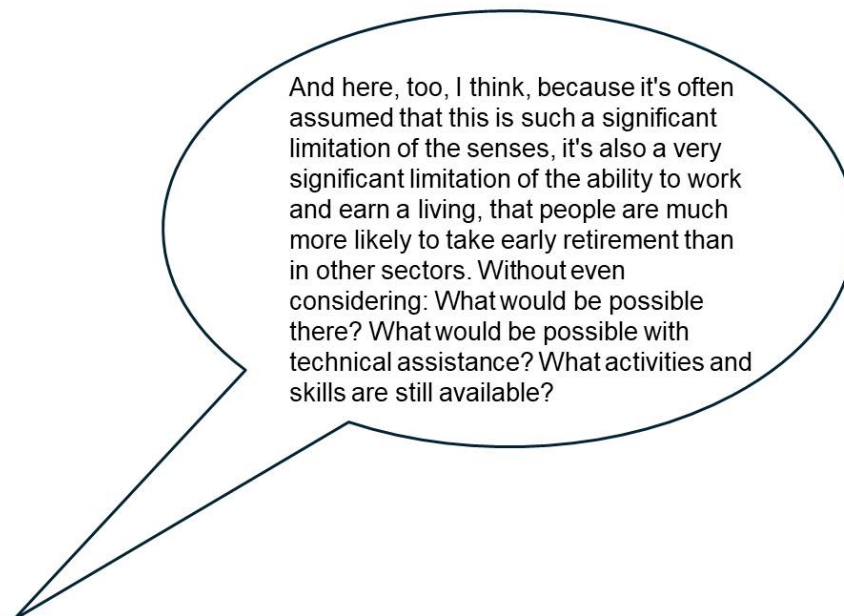
In general, specialist advisors confirm that they have limited contact with people with DSI in the workplace. Only a few of those surveyed have knowledge of dual sensory impairments or experience of working with this diverse group. Therefore, basic information on hearing and vision impairment in the workplace is also considered necessary for advisors. The same applies to employees at rehabilitation providers and integration/inclusion offices, so they can understand individual problems, assess needs, and offer appropriate services.

The questions asked by the specialist advisors mainly relate to the following topics:

- How can I optimise my counselling for people with DSI and their needs?
- Where can I turn if I lack background knowledge about deafblindness and hearing and visual impairment?
- What specific vocational and medical rehabilitation services are available?

→ **Limited participation**

The way in which individual needs for participation are determined was reported to be often unclear to all groups involved in the study. The decision-making process appears to lack transparency. The assessment of needs appears to be based on files compiled by doctors or psychologists, for example. The same applies to decisions on applications for reduced earning capacity pensions, which are made by doctors employed by the pension insurance scheme. People with DSI were mostly not involved, or only marginally involved, in the decision-making process. According to the study's participants, comprehensive needs assessments and consideration of possible prospects are often not carried out due to a lack of background knowledge on deafblindness and hearing and visual impairment, as well as specific assessment tools.



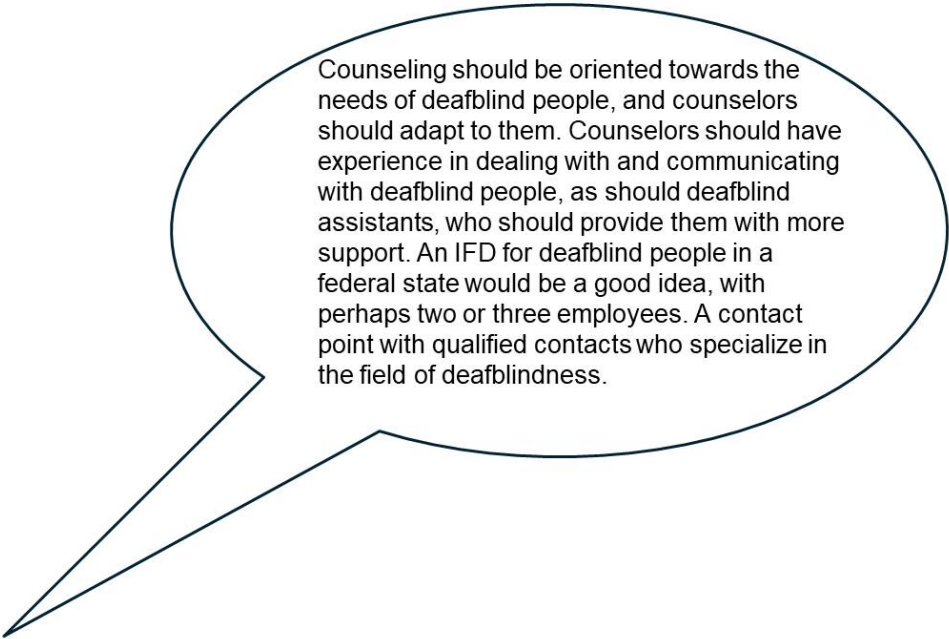
Quote from a specialist advisor (source: EMPLOY interviews, 2023)

In the context of a needs assessment, for example in counselling, limited participation can be assumed for people with DSI in this process. It is still considered necessary to carry out an individual, specific assessment of the resources and participation needs of people with deafblindness/hearing and vision impairment.

→ Deficits in specific counselling and rehabilitation services

There is a lack of services specifically tailored to the needs of deafblind and hearing-impaired people, provided by staff with the necessary background knowledge and communication skills. This includes counselling and vocational (as well as medical) rehabilitation services.

The people with DSI surveyed considered advice on individual entitlements and rights in working life, as well as individually tailored assistance for everyday working life (aids, workplace equipment, assistants and interpreters), to be urgently necessary. They also expressed the need for advice on dealing with psychosocial stress and managing deafblindness and hearing and vision impairment. Peer counselling and self-help services were mentioned as being particularly helpful in this context. However, currently, only a few institutions specifically target this group. These include the following services, but the list is not exhaustive: KSL-MSi (Competence Centre for Independent Living for People with Sensory Disabilities, Essen, North Rhine-Westphalia); BLISTA (National Competence Centre for People with Blindness and Vision Impairment, Marburg, Hesse); and ITM (Specialist Service for the Integration of Deafblind and Hearing-Impaired People, Munich, Bavaria). Some of these services are only available in certain federal states.



Counseling should be oriented towards the needs of deafblind people, and counselors should adapt to them. Counselors should have experience in dealing with and communicating with deafblind people, as should deafblind assistants, who should provide them with more support. An IFD for deafblind people in a federal state would be a good idea, with perhaps two or three employees. A contact point with qualified contacts who specialize in the field of deafblindness.

Quote from a person with DSI (source: EMPLOY interviews, 2023)

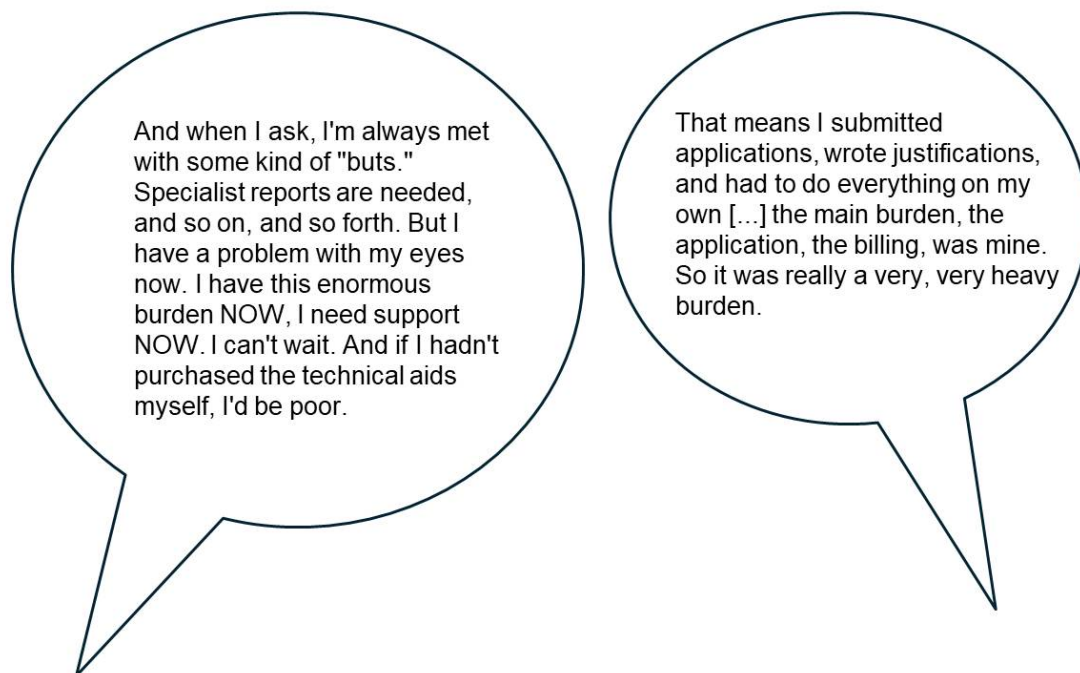
Vocational rehabilitation measures are offered by the German Deafblind Association in Hanover, among other places. As part of the Wege in den Beruf (Paths to Employment) project, Nikolauspflge in Stuttgart developed vocational counselling and training services in cooperation with the German Deafblind Association (es Taubblindenwerk) and the SFZ Förderzentrum Chemnitz.

Both people with DSI and specialist advisors surveyed, stated that services are either too few or not well known. Opportunities to find rehabilitation tailored to individual needs close to home are rare.

Since advice on individual opportunities in the workplace and appropriate rehabilitation services are often fundamental prerequisites for satisfactory retention in working life, there is an urgent need to expand such services with the possibility of flexible adaptation.

→ **Lengthy application and approval process for benefits**

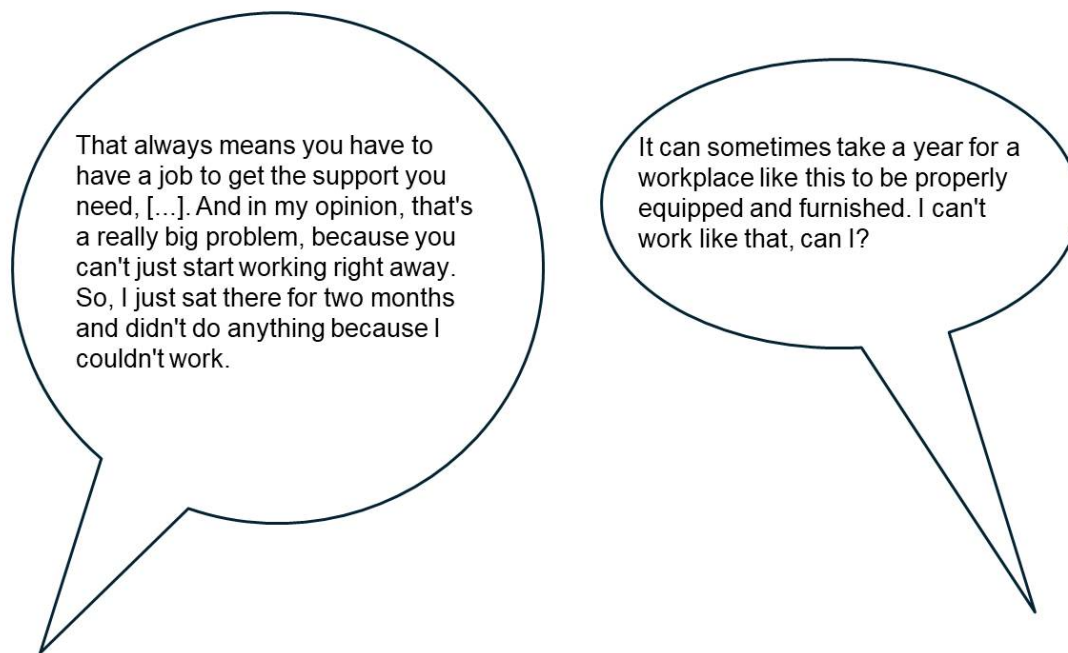
Doing one's own research to obtain information about application procedures and the application process itself results in additional burdens and a very high time commitment.



Quotes from people with DSI (source: EMPLOY interviews, 2023)

With regard to applications and approvals, it is particularly noted that the long waiting times and bureaucratic hurdles involved in applying for workplace equipment are a problem. Timely and uncomplicated approval of benefits is required.

In addition, the long waiting times for approvals make it difficult to bridge periods without assistance at work. This can jeopardise employment, particularly during critical phases such as the probationary period.



Quote from a person with DSI (left) and a specialist advisor (right) (source: EMPLOY interviews, 2023)

Regarding the application process and funding for services to support participation in working life, specialist advisors confirm that people with DSI often experience lengthy approval times.

→ **Cooperation and networking**

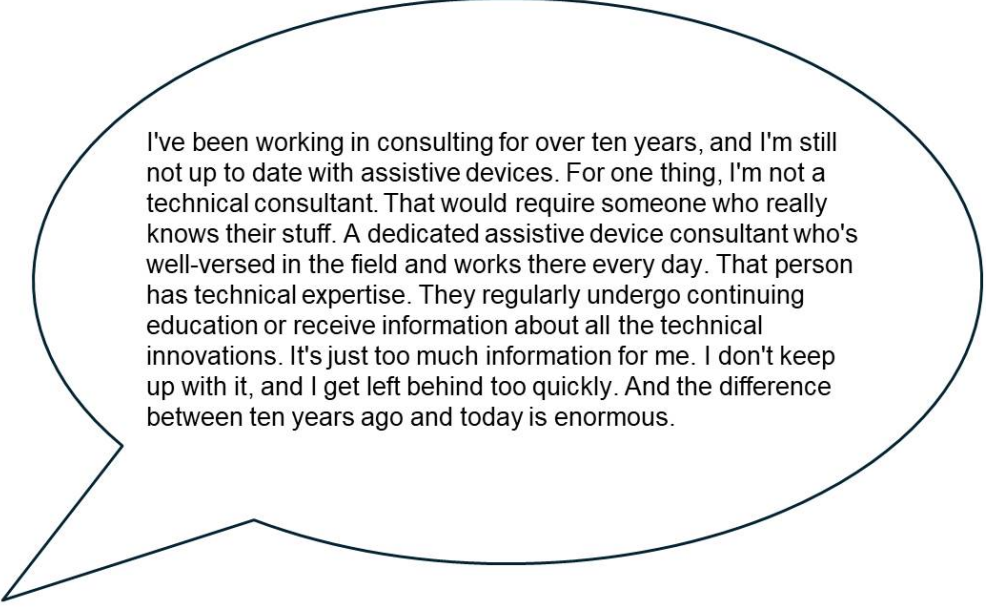
Some federal states have integration/inclusion services for people with hearing impairment, and sometimes for those with vision impairment. Joint counselling is sometimes organised for people who are deafblind or have hearing and vision impairment. However, there are generally no institutionalised forms of cooperation, and cooperation depends on the lead counsellor's assessment. Even if the expertise in the areas of hearing impairment and visual impairment is combined in a joint counselling session, it should be noted that deafblindness or hearing and vision impairment is not a mere addition of two disabilities, but requires specific expertise in the dual sensory impairment.

In the absence of adequate information, most specialist advisors tend to seek out experts or institutions when confronted with the topic of deafblindness or hearing and vision impairment. These networks are typically based on personal relationships within their own institution or organisation. Many of those surveyed criticise the abolition of the EUTBs (supplementary independent participation advice services) in Germany, which were specifically geared towards deafblindness and hearing and vision impairment, and staffed by peer advisors. The EUTBs in Germany were widely used as a source of information on deafblindness and hearing and visual impairment. However, the EUTBs did not specialise in participation in working life.

→ **Vision: Central point of contact with expertise on deafblindness and hearing and vision impairment in the context of working life**

In view of the heterogeneous target groups and the highly diverse individual resources and needs associated with them, as well as the deficits in information, advice and networking identified by all those involved, representatives of all the surveyed groups propose the establishment of a centralised body to provide information and facilitate networking at a national level.

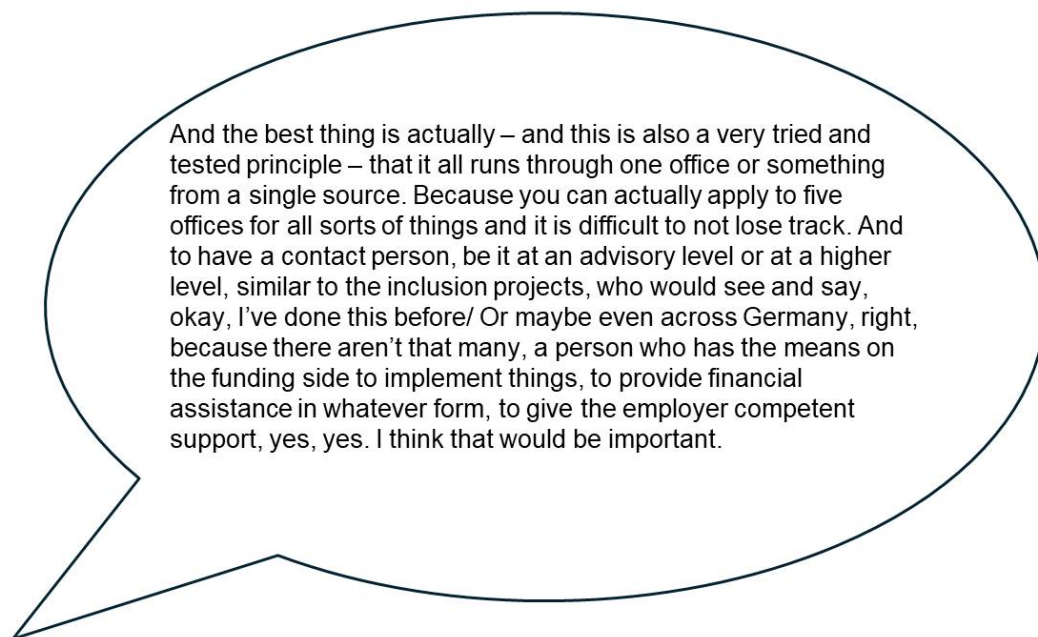
To create synergies, it is proposed that a contact point with specialist expertise collects, updates and makes available current information centrally. This information could then be accessed as required. This also applies in particular to technical aids, as developments in this area are particularly rapid, in addition to the topics of the effects of dual sensory impairment, and the possibilities for decentralised counselling and rehabilitation.



I've been working in consulting for over ten years, and I'm still not up to date with assistive devices. For one thing, I'm not a technical consultant. That would require someone who really knows their stuff. A dedicated assistive device consultant who's well-versed in the field and works there every day. That person has technical expertise. They regularly undergo continuing education or receive information about all the technical innovations. It's just too much information for me. I don't keep up with it, and I get left behind too quickly. And the difference between ten years ago and today is enormous.

Quote from a specialist advisor (source: EMPLOY interviews, 2023)

This pooling of information could also enable cost bearers to make informed and swift decisions on approving benefits for participation in working life.



Quote from an expert advisor (source: EMPLOY interviews, 2023)

6. Materials: Information brochure and assessment tool for determining participation needs

Based on the results of the EMPLOY data collection, various materials were developed to improve participation opportunities for people with deafblindness or hearing and vision impairments. These include an information brochure providing comprehensive information on deafblindness and hearing and visual impairment in relation to working life, as well as a tool for adequately assessing and documenting the participation needs of people with dual sensory impairment for use in counselling situations. Both publications were subject to formative evaluation during the development process, involving all target groups. For example, a preliminary version of the materials was presented and discussed in three focus groups.

6.1 Information brochure

The information brochure "Perspectives in the workplace – making meaningful use of prospects" with the subtitle "How to shape the participation of people with deafblindness/hearing and vision impairment in working life" has been published in the REHADAT-Wissen series.



cover page

The brochure is intended for the various target groups of the project (see Chapter 2.1), including specialist advisors, people from the working environment (such as employers and colleagues), and people with deafblindness/hearing and vision impairment. The 124-page brochure is divided into six chapters: The first chapter introduces the EMPLOY project, while the second chapter provides information about deafblindness and combined hearing and vision impairment. The third chapter describes the challenges experienced by people with DSI in the workplace. The fourth chapter presents solutions to some of these challenges. The fifth chapter deals with the topics of 'support, counselling and disability pensions', and the final sixth chapter consists of an extensive collection of further addresses and literature. Text-structuring elements such as info boxes and checklists highlight information that is of primary importance for a specific target group, making it more accessible.

To ensure the long-term availability of the information brochure, the Rehadat database project was brought on board as a partner. The brochure was published as the 16th edition in the Rehadat-Wissen series and will remain available online at rehadat-wissen.de once the project has ended. It can be downloaded free of charge as a PDF and is available in print.

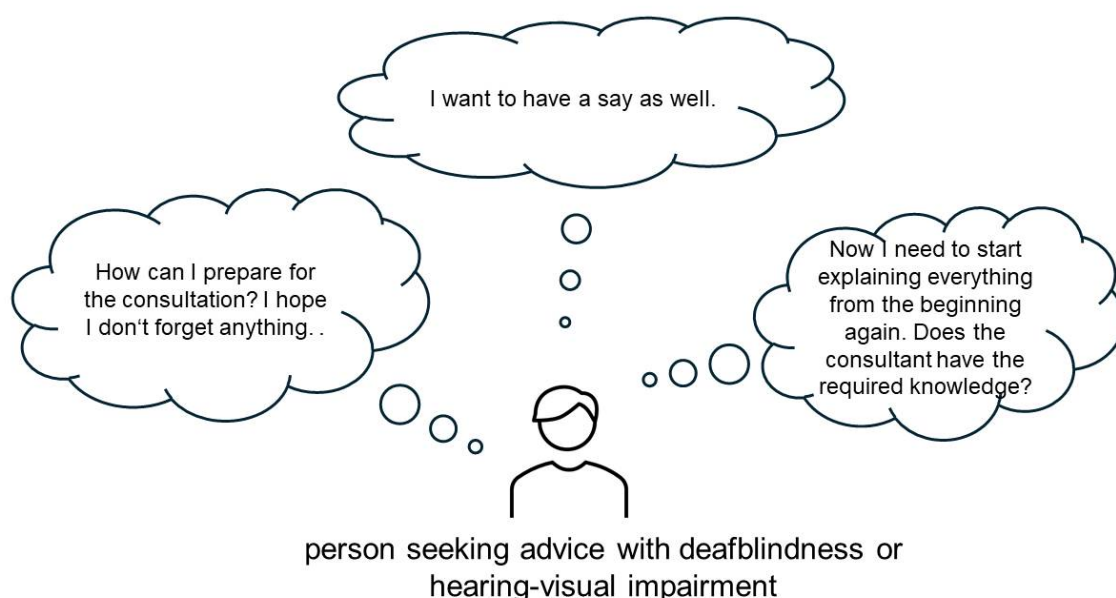
Important aspects of the chapters have been made available in sign language videos to ensure barrier-free access to the contents of the brochure. These can be accessed in the online version via a sign language button. In the PDF version and printed edition of the brochure, the videos can be accessed via a QR code. The online version of the brochure also supports enlarged display and user-defined colours. It is optimised for use with screen readers and can be operated using only the keyboard.

6.2 Tool for determining participation needs

The tool for determining the participation needs of people with DSI comprises two accessible documentation forms. The tool focuses on supporting counselling practice and determining the needs of people with deafblindness and combined hearing and vision impairment in relation to working life.

The **self-assessment questionnaire** enables people with deafblindness/hearing and vision impairment to systematically record their personal needs in relation to working life. The completed questionnaire can be taken to a counselling appointment, for example. It consists of six modules: communication; current professional situation; experiences at work; aids in the workplace; assistance and support options; and wishes and goals for working life.

The questionnaire is available here as an accessible PDF, including a German sign language translation, and can be used in analogue or digital form.



Aspects of the self-assessment questionnaire

The **documentation form for the counselling context** is intended for counsellors. In the context of data collection for the EMPLOY project, it has become apparent that there are only a few specialised counselling centres for people with dual sensory impairment (DSI) in Germany. This group is often supported by counsellors who have little or no information about the target group and are not specialised in hearing or vision impairment. In such cases, the documentation form can support counselling practice by providing counsellors with a template to guide them in asking people with deafblindness and combined hearing and vision impairment about their specific needs. The form consists of six modules:

- Information on the disability
- Communication
- School, career and vocational training
- Vocational rehabilitation and other support measures
- Resources, challenges in the workplace and goals for working life
- Further action

The form is available as an accessible PDF file [here](#), including an introduction in German sign language, and can be completed in analogue or digital formats.



Aspects of counselling people with dual sensory impairment

The two documentation forms were developed because the complex needs of people with dual sensory impairment are often not fully recognised, meaning they may not receive adequate support. The forms offer a systematic way of identifying individual needs and resources, which is the first step towards providing tailored support. Both forms are based on data collected as part of the EMPLOY project, and are designed

according to ICF-based assessment forms used by various German federal states for integration assistance.

The counselling practice documentation form and the self-assessment questionnaire are available in the information brochure and can also be downloaded from various websites, including the self-help website.

6.3 Accessibility aspects

The creation of both the information brochure and the assessment tool for determining participation needs presented challenges. They both had to be designed in terms of content, language and technology to meet the needs of the various target groups. The topics for the **information brochure** were preselected based primarily on the evaluation of the interviews and the project's online survey (see Chapter 4). Initial texts were then drafted and agreed upon in three focus groups, involving two of the three target groups: advisors and people with DSI.

A balance was sought between everyday language and technical terminology when formulating the texts, in order to reach all target groups. To make the information brochure accessible to all, summaries of the chapters were provided in DGS videos for deafblind and deaf people who use sign language. The participatory needs assessment tool included a **self-assessment questionnaire** in written and sign language, and a **documentation form for counselling contexts** with an introduction in sign language. Deaf sign language interpreters were commissioned to translate the texts into DGS, working alongside the project team. The same requirements for video production as for the survey videos were met in this process. The DGS videos are available online via a button and in PDF format via a QR code. IT specialists developed a technical function that replaces the DGS buttons with QR codes when creating a PDF from the online edition, specifically for the Rehadat-Wissen edition on deafblindness and hearing and visual impairment. Both publications have been optimised for use with screen readers and, in consultation with the target groups, have been given preferred colour contrasts for use in dark mode, such as white text on a black background.

7. Further needs and recommendations for action

In order to meet the needs of deafblind and hearing-impaired people, participatory and adaptive research approaches are essential. The insights gained from the EMPLOY project regarding recruitment, accessibility, and methodological implementation can inform future research projects in this context.

In summary, the EMPLOY project identified the following central needs for improving the participation of deafblind and hearing-impaired employees in working life:

Employees with deafblindness and combined hearing and vision impairment, their colleagues, employers and supervisors, as well as their advisors and assessors, require expert information and advice. This includes specific knowledge on assessing the impact and needs of rehabilitation providers, integration offices/inclusion offices, and their specialist services. The participation of people with dual sensory impairment in needs assessments and decisions regarding professional development or transition to disability pensions must increase. Specific vocational (and medical) rehabilitation services must be expanded.

The EMPLOY project has developed and distributed nationwide building blocks for information and improved participation, which are available on the Rehadat platform on a long-term basis.

In addition to these important building blocks for improving participation, there is an urgent need for personalised counselling and an expansion of specialised counselling and rehabilitation services to meet the needs of people with dual sensory impairment.

High-quality counselling requires an in-depth understanding of combined sensory impairment and effective communication skills. It is not realistic to provide specific counselling services across the board for the small and very heterogeneous group of people with deafblindness/hearing and vision impairment in working life, who have very specific communication requirements. Therefore, it is necessary to establish a nationwide, supra-regional specialist centre for hearing and vision impairment, deafblindness, and participation in working life. This centre would serve as a point of contact for people with deafblindness and combined hearing and vision impairment, specialist advisors, and individuals in the working environment. Its tasks would include:

- Providing information and education (e.g. providing up-to-date information on technical aids, raising awareness in the workplace)
- Forwarding to specialised counselling and rehabilitation services, in particular to peer counselling
- Networking all relevant stakeholders (e.g. by organising conferences or distributing a newsletter)
- Offering further training for specialist advisors at rehabilitation providers, inclusion offices and specialist services (transfer of specific knowledge)
- Enhancing information and education, expansion of existing services with a focus on people with dual sensory loss, and a national agency with an overview of current developments and services are important prerequisites for enabling deafblind and hearing-impaired people to participate satisfactorily in working life.

Providing information and education, expanding existing services with a focus on people with DSI, and establishing a national office to oversee current developments and services are essential steps to enable people with deafblindness/hearing and vision impairment to participate satisfactorily in working life.

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