

Prospects for improving the situation regarding the care of elderly people who are deaf

Authors: Prof. Dr. Thomas Kaul, Nele Büchler, Anne Gelhardt und Frank Menzel (†)

University of Cologne

Faculty of Human Sciences

Education and Rehabilitation of the Deaf
and the Hard of Hearing

The following recommendations are a guide to improving care structures for elderly people who are deaf – on different levels, and adaptable according to specific regional conditions. They were developed at the University of Cologne, in the field of pedagogy and rehabilitation of people with hearing impairments, in the context of two projects for sustainable improvement of care structures for elderly people who are deaf. This was carried out between 2006 and 2017, on behalf of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (the BMFSFJ) in close cooperation with deaf experts. The primary objective is the structural improvement of the situation for elderly deaf people, through information, education and quantitative and qualitative expansion and development of suitable services for this target group. The establishment of a Regional Centre of Competence for Elderly People who are Deaf (GIA Competence Centre) is recommended to improve the care situation. It would serve as a contact and information point for the federal state. On the one hand, it would serve as a link between the existing counselling and care structures for the elderly, and on the other, it would form the counselling and care structures of elderly people who are deaf. Given the very different structural framework conditions and resources in the individual federal states, the implementation would be organised differently, for example with regard to staffing and infrastructure. The term GIA Competence Centre used in these recommendations for action, refers not only to the concept developed in the model project, but also to other forms of a state-wide, specialised authority for elderly people who are deaf.

The focus is on elderly people who are deaf. This refers to people who became deaf before the acquisition of language, and who use sign language. Certain parts of the following information can also be used or adapted, in consultation with the respective self-help associations, people who are hard of hearing, people who have become deaf, and people who are both deaf and blind.

Deaf people in old age

Deaf people are defined as people who have been deaf since birth, or who lost their ability to hear before they learned to speak. Since deaf people, in contrast to people who are hard of hearing, are unable to hear speech via their sense of hearing with hearing aids, the language acquisition in terms of spoken German, and therefore also of written German, is considerably restricted. Deaf people prefer to communicate by means of German Sign Language. This language not only enables them to enjoy informal communication and social interaction with other deaf people. It is also the basis for the exchange of information and the acquisition of coping skills. Due to the high status of German Sign Language, the social network of the deaf community plays a central role. For example, for deaf people, leisure activities take place almost exclusively within own their language and cultural group, all the way into old age.

In terms of direct contact with hearing people, the communication options are often limited. Initially, the perception of spoken language is only possible for deaf people by lip reading. However, this form of communication is very susceptible to misunderstandings and, above all, it is not suitable for relaying complex messages. Insofar as hearing people have not mastered German Sign Language, the use of sign language interpreters is another way to ensure communication. Since they have to be booked long-term, short-term appointments for spontaneous meetings are not easy to arrange. Furthermore, there is no entitlement to benefits for many everyday situations, which means that deaf people have to bear the costs themselves; this often leads to their waiving the services of an interpreter. However, because this occupational profile is still relatively young, older deaf people, in particular, have little experience in the use of professional interpreters. That is why older deaf people use their services less often, even if the costs are taken over. Utilising interpreters who are experts in the field of interpreting for older deaf people – professionals who can assess both their expectations and their application of the language, creates favourable conditions for their use.

The situation regarding the care of elderly people who are deaf

The need for different services to support the elderly is also very high among deaf people. However, there are hardly any services that meet the communicative and cultural needs of this target group. The situation regarding the care of elderly people who are deaf must, therefore, be considered deficient. Uncertain communication situations and a lack of background knowledge about deaf people on the part of professionals, constitute a considerable barrier regarding the

utilisation of different services. This is compounded by the fact that professionals are not adequately informed regarding specific services that are available to elderly people who are deaf, and they are therefore often unable to address their specific needs. Due to the limited access to information, deaf people are not aware of general entitlements and services and are therefore unable to take advantage of them. The care structure must be fundamentally improved to ensure participation and self-determination, according to the UN Convention on the Rights of Persons with Disabilities for elderly people who are deaf. For example, unhindered access to existing general services for the elderly should be made possible by the commissioning of sign language interpreters. However, a service that meets the communicative and cultural needs of elderly people who are deaf would be more comprehensive. This requires functional expertise concerning the needs of elderly people who are deaf; above all, this includes knowledge of the conditions regarding socialisation for deaf people and excellent German sign language skills. Such specific services are relatively rare. In fact, they exist almost exclusively in residential housing situations and mostly regionally, primarily in larger cities. The situation regarding the care of deaf people who suffer from dementia is particularly challenging. Due to a lack of diagnostic tools, insufficient knowledge about the target group and their special-needs on the part of the treating physicians and limited treatment options, it is obvious that it often results in misdiagnoses and inadequate care during all stages of the disease.

Need for action

The goal is to improve the situation regarding the care of elderly people who are deaf; this ought to be implemented on three levels.

- **Improvement of care structures:** Access to the existing care network needs to be ensured for older people with special life circumstances. If this is not possible, due to the unique requirements of the target group, specific services should be provided instead.
- **Information and education:** Deaf people must be given access to information on care entitlements and dementia benefits. The various people involved in the care process, especially the medical staff and nurses, should be informed about the specific needs of deaf people.
- **Counselling:** Deaf people need competent advice in specific situations, that meet their cultural and communicative needs.

Apart from expertise in the areas of care and dementia, the implementation of these three main areas of action requires a high level of expert knowledge, especially regarding the prerequisites for and communicative and cultural needs of elderly people who are deaf. To ensure that there is a common understanding of these requirements and to guarantee that the fulfilment of the requirements is transparent to the target group, it is necessary to develop quality criteria for sustainable quality assurance.

Improvement of the care situation

The GIA Competence Centre model

The concept of the GIA Competence Centre was developed to sustainably improve the situation regarding the care of elderly people who are deaf. The GIA Competence Centre is a model for a specialist department, with the primary objective of improving the situation regarding the care of elderly people who are deaf. It is a concept that can be adapted according to regional conditions and, depending on the structure in which it is embedded, it might have a different designation.

The GIA Competence Centre is a specialised department that functions as a link between the general care structures for the elderly and the deaf. This enables existing structures to be linked, and synergies to be used to avoid parallel structures. The work of the GIA Competence Centre is aimed at different target groups: elderly people who are deaf, their relatives, institutions for the general care of the elderly, and institutions that offer services for deaf people.

A sustainable improvement in the care situation must be geared towards the needs of deaf people. The following fields of action have priority here:

- Improvement of the care structure
- Information and education
- Consultation and mediation

The field of action, *Improvement of the Care Structure*, has priority. Existing services for people with dementia and those in need of care, must be made accessible to deaf people or if necessary, specific services must be created. The objective is to improve care structures in the areas of nursing, dementia, age-appropriate living conditions and preventive treatment for elderly people who are deaf, and have both dementia and long-term care needs, and for their relatives. This

must be done by instructing responsible people to fulfil the communicative and cultural requirements within a service.

In the field of action, *Information and education*, the GIA Competence Centre contributes towards informing deaf people and different institutions and parties, or towards educating them on a specific topic. For deaf people, issues such as care, dementia and age-appropriate living, as well as questions about preventive medicine, are priorities. Senior citizens residences, nursing services, doctors, etc. must be informed about the unique needs and conditions for socialisation that affect people who are deaf. The GIA Competence Centre must ensure that there is adequate communication regarding information and education services, for example with sign language or for written information in a form that takes into account the specific requirements pertaining to deaf people in the acquisition of written language.

In the field of *Consulting and Mediation*, the GIA Competence Centre advises individuals and institutions on request, regarding a specific situation and, if necessary, passes it on to a relevant service provider. Because the GIA Competence Centre serves as a starting, coordination and mediation point, the focus is on redirecting people who approach them to the relevant institutions. The task is to guarantee free access within the process, and to ensure that the necessary competence is available to both the person who is seeking advice and the counsellor.

Structure of a GIA competence centre

Analysis of regional structures (field analysis)

In order to set up a GIA Competence Centre in a federal state, the structural requirements should first be analysed and documented. The analysis outlines the situation regarding the care of elderly people who are deaf and names the responsible contact people in the areas of assistance for deaf people and general aid for the elderly. This includes, for example, representatives of relevant ministries and the state official for people with disabilities. An analysis of the legal framework and funding programmes of the federal state could provide information on options for financing a GIA Competence Centre.

Informing and convincing relevant actors

To ensure that the perspective of deaf people is given adequate consideration, contact with the Regional Association for the Deaf should first be sought. The next step is to contact the political

representatives, potential providers of funds from the relevant ministries and health insurances, as listed in the field analysis, and to invite them to an information event, ideally in cooperation with the Regional Association for the Deaf. The objective is to inform them regarding the communicative and cultural conditions, and the needs of elderly people who are deaf, and to draw their attention to the need for a GIA Competence Centre.

Identifying potential supporters

The institution that assumes responsibility for a GIA Competence Centre, should have experience in the submission of project applications and the handling thereof, and in human resources management. To facilitate access to the target group, it makes sense to hand over a GIA Competence Centre to a responsible body that has the required expertise in counselling and caring for the deaf, and which already offers suitable services, such as a social counselling centre for the deaf. This means that the target group is already familiar with the responsible body, and synergies can be utilised. If it is intended, that the responsibility be transferred to an institution with a focus on the care of people with dementia, or the elderly, the networking and cooperation with the regional care structures for deaf people must be guaranteed. Close cooperation with associations such as the respective Regional Associations for the Deaf, is indispensable in every case.

Checking funding options and submitting applications

To examine possible methods of financing a GIA Competence Centre, further discussions are required with representatives of the relevant ministries or other potential providers of funds, such as the Care-Giving Fund. The objective is to inform those involved about the situation of elderly people who are deaf, and to discuss the necessary improvement of the care situation. The GIA Competence Centre's concept should be presented here, and financing options should be coordinated. After that, the application can be submitted.

Methods of implementation can be rather heterogeneous, and they are heavily dependent on the local conditions in the respective federal states. In essence however, there is a decisive parallel which, despite the diversity of the framework conditions, applies across all federal states. In order to initiate and guide the process of implementation, someone who is familiar with the underlying issue and the relevant structures must take responsibility for working towards achieving these goals and coordinating the entire process.

Setting up the GIA Competence Centre: Structural requirements

In view of the special features of the target group, minimum requirements for unhindered communication and access to the GIA Competence Centre must be met.

The GIA Competence Centre should be well situated in terms of traffic connections. Access should be as free as possible. An office with facilities for private counselling – which sometimes involves groups of several people – is required. In order to ensure unhindered access, the specialist consultants in the GIA Competence Centre should be reachable by email and computer-based video communication. Further information can be found in the quality requirements.

Hiring staff

The tasks of a GIA Competence Centre should be carried out by a qualified specialist counsellor with relevant professional qualifications (for example in social work, education or a comparable discipline). The scope of the job should be adapted to the local conditions in the respective federal states, as required. The skills required by the specialist consultants can be derived from the requirements of the target groups and the various fields of activity. They include both expertise and experience in dealing with the target group 'deaf people', and knowledge regarding the target group 'elderly people with care needs and dementia'. Further information can be found in the quality requirements.

Quality assurance

Apart from quality guidelines for nursing and care, services for elderly people who are deaf must also meet certain criteria relating to communication and interaction with deaf people. As no quality criteria regarding the special needs of elderly people who are deaf currently exist, a working group for quality assurance has drawn up a list of basic quality criteria for the care sector, including concrete examples...

Assessment of whether or not a service is suitable, should ultimately come down to the wishes of the person concerned and his/her individual resources, needs and desires. Nevertheless, basic quality requirements can be formulated for services that will adequately meet the needs of elderly people who are deaf. Employees must be appropriately qualified in order to meet these criteria. Furthermore, the infrastructure and equipment must enable unhindered access.

To ensure confident and comfortable communication with patients in need of care, employees must be highly competent in terms of sign language, and they should possess additional communication skills. This includes both sign language and written communication. In addition to this, the targeted use of and the ability to interpret body language is of great importance, especially regarding people with dementia, who are no longer able to communicate linguistically anymore. Communicative skills must be so highly developed, that they are able to assess and adapt to the way older deaf people use sign language. They must also be effectively trained to detect possible communicative changes due to illnesses or other disabilities such as dementia.

In order for deaf people to be treated with dignity and respect, knowledge of not only the patient's individual biography, but also of the social culture of deaf people and intercultural skills are helpful (*Deaf Awareness*). This includes, in particular, knowledge of the life and social conditions of elderly people who are deaf, for example, their experiences with National Socialism, such as discrimination against sign language and possible forced sterilization. Employees should also be familiar with the networks and resources within the deaf community and with counselling and rehabilitation services, interpreter agencies and associations in the sign language community.

The spatial and infrastructural conditions must be designed in such a way that they meet the environmental and communicative requirements of deaf people (*Deaf Space*). This includes good lighting conditions and the possibility for all those participating in a conversation to see each other well, for example, sitting in group circles.

Acoustic signals such as bells, knockers or alarm clocks, as well as alarm signals, must be perceptible by visual indication, by vibration or by drafts of air. Regarding possibilities for communication and access to information, various requirements have to be fulfilled: Wi-Fi should be available, particularly in terms of housing offers, in order to facilitate communication and access to information via Skype or video chat, because more and more deaf people who are elderly are taking advantage of the communicative opportunities offered by the internet. In order to enable communication in sign language, a facility must also be reachable by email, and ideally also via Skype or telephone relay service. Information media should be accessible in sign language at different levels, including easy sign language analogous to easy language.

Conclusion and prospects

The UN Convention on the Rights of Persons with Disabilities calls for equal participation in society for all people with disabilities. An essential prerequisite for this is that, where possible, all people with disabilities, in all walks of life, should have unhindered access to the care system. However, services that are inclusive for all target groups are unable to fully meet the specific needs and requirements of each target group. This is especially true for deaf people, who have different needs due to their particular linguistic and cultural life situation. Deaf people need specific services that are especially tailored, both linguistically and culturally. This must be anchored in sign language, include access to the sign language community and take the individual's visual perception into consideration.

However, there is currently no guarantee that deaf people will be able to utilise a service that matches their communicative and cultural resources and needs. This applies to all areas of significance for elderly care, such as inpatient and outpatient care, counselling, therapy and diagnostics.

Further efforts are therefore needed to sustainably improve the situation regarding the care of elderly people who are deaf. General facilities can only partially meet the needs of a target group with such specific communicative and cultural requirements. Sign language interpreters are an important communicative aid, but on their own, do they not guarantee the expert consulting or treatment that is needed. Specific services that are primarily used by deaf people, need to be expanded, and they require consistent and transparent quality standards.

Improving the situation regarding the care of elderly people who are deaf requires professional, specialised support that both initiates and accompanies the necessary processes of the federal state. Such a task cannot be provided on a voluntary basis. As part of the GIA project (2011-2014), GIA Competence Centres were established in NRW and Saxony. The evaluation of the project showed that the two model Competence Centres have not only successfully implemented the necessary processes to improve the care situation. They have also initiated new services and utilised different measures to raise awareness of deafness in old age.

Therefore, the processes for setting up a GIA Competence Centre should continue to be pursued in each federal state in the future. In the process, the respective structural requirements must be taken into account. If the establishment of a GIA Competence Centre cannot be implemented in

a federal state, alternative approaches should be developed to implement the urgently required measures to improve the situation regarding the care of elderly people who are deaf.

To guarantee the quality of services and programmes for elderly people who are deaf, the process of developing quality assurance measures initiated in the GIA 2.0 project must be continued. To this end, criteria and verifiable indicators for the central areas of care, counselling and diagnostics and therapy should be further developed and implemented in existing quality assurance systems in nursing and health care. Fulfilling these quality requirements might involve higher costs. These result, for example, from higher time-expenditure during care-giving processes or larger catchment areas for outpatient care services and the associated travel costs. It remains to be determined who will bear the costs for this additional expenditure or in whose area of responsibility this falls.

During the GIA 2.0 project and the previous projects, the focus was on the situation and needs of elderly people who are deaf. At different points in the project, it became clear that individuals with other hearing impairments, such as those who are hard of hearing, those who have become deaf, and those who are both blind and deaf, experience similar or comparable barriers in old age. We therefore also need to look into the extent to which the formulated measures and quality requirements for improving the situation regarding the care of elderly people who are deaf are also relevant to the other target groups, how they could be adapted where appropriate and who could implement the required changes.

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Universität zu Köln
Department Heilpädagogik und Rehabilitation
Projekt GIA
Prof. Dr. Thomas Kaul, Nele Büchler, Anne Gelhardt
Klosterstraße 79b
50931 Köln
Germany

projekt-gia@uni-koeln.de
www.kompetenzzentren-gia.de



Gefördert vom:

