Availability and accessibility of healthcare for deaf and hard of hearing patients

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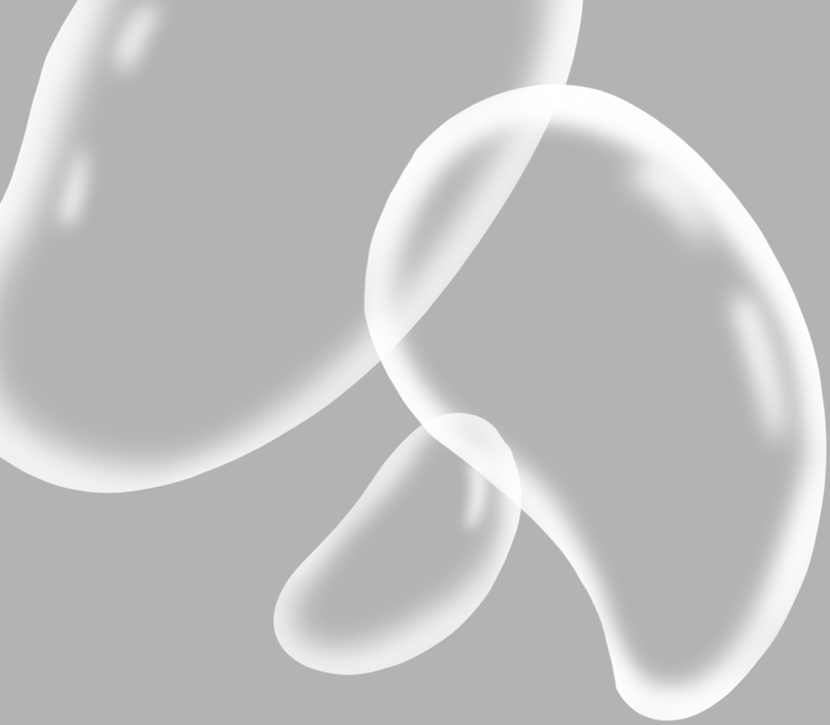

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Health related quality of life of people who are deaf or hard of hearing

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Abstract

Purpose: Patient groups and healthcare workers report that people who are deaf or hard of hearing (DHH), have poorer health and wellbeing. The aim of this study is to gain insight into the health of DHH people in the Netherlands.

Methods: The physical and mental health of participants was measured using the World Health Organization Quality of Life- Bref scale (WHOQoL-BREF). Participants filled out an epidemiological questionnaire and questions about the mode of language they generally use. All questionnaires were translated into two versions of Sign Language of the Netherlands (NGT) according to a forward-backward translation protocol, a written version and a sign supported Dutch (SSD) version of the questionnaire were also provided.

Results: The questionnaires were completed by 274 DHH people. Both deaf and hard of hearing people, regardless of the age of onset, reported having poorer physical health than their hearing peers. Hard of hearing people reported more psychological difficulties than control group.

Conclusions: It is important that DHH people are recognized as a patient group with specific health problems. More research into the nature and effects of this specific health problems is needed. The creation of more awareness of these health problems among DHH people and their healthcare workers is essential.

Introduction

Healthcare workers and patient groups widely report that people who are deaf or hard of hearing (DHH) have a poorer health related quality of life than hearing people. The reason they most often put forward is that DHH people experience barriers in accessing healthcare, with substantial consequences for their health and wellbeing. Several authors have described barriers that may have a negative impact on the health of DHH people (1-4). These barriers may vary, depending on residual hearing, the age of onset of the hearing loss and the degree to which the individual accepts and uses available support such as amplification, sign language interpreters or speech to text interpreters. Possible barriers that have been described so far in the literature are:

Barriers due to reduced medical knowledge

Among hearing people much health information is circulated during informal conversations and from overhearing these exchanges (implicit learning). DHH people do not have access to this type of ambient information and therefore miss out on much knowledge (5-8). As for explicit learning, e.g. in education, most children with severe DHH used to have only limited exposure to health information in schools (9), because there is often a predominant focus on language development and practical language skills, at the cost of subjects such as biology.

People who function severe DHH from an early age often develop low language and literacy skills (10-12). Literacy skills are low because when sounds of a language (phonemes) cannot be heard, there is no logical correlation between a given concept and its written form (letters/characters). The only option is to memorize which combinations of letters are used and in which order, to describe this concept. These people also cannot use vocalization when reading either. This means that only those words that they have previously read and of which they have memorized the character construction can be read fluently. This contributes to the limited knowledge often experienced in DHH.

Communication barriers

Even a highly skilled lip-reader is able to ‘read’ only 20-40% of what is said (13). This suffices to follow a fairly predictable conversation in common everyday circumstances. However, during a medical consultation, when many unknown terms are used and the patient may be stressed, this method often proves to be inadequate (10, 12). The use of speech-to-text interpreters and/or sign language interpreters in medical settings may help overcome these barriers. These supports are not always routinely used and the amount of information transferred from the physician to the patient and vice versa is therefore restricted (14). Communication barriers may also pose logistic problems; for instance to make an appointment or ask for a repeat prescription it is often necessary to contact the physician's office by telephone or go there in person.

Deaf cultural barriers

People who are deaf or hard of hearing from a young age have many characteristics in common (15, 16). Due to limited access to spoken language and limited acceptance of sign language worldwide, they tend to form a cultural-linguistic minority group within the hearing population which is referred to as the 'Deaf community'. This community has its own norms and values which may compromise healthcare access in the same manner as cultural and language barriers influence healthcare access of ethnic minority groups (14).

Attempts are being made to create awareness of these barriers among healthcare providers. Advice for health workers includes booking a longer consultation time, exploring the optimal mode of communication with the patient and hiring interpreters. It extends to creating specialized facilities and using special information and communication technology (ICT) programs to support communication and education (1).

The aim of this study is to gain insight into the state of health of DHH people in the Netherlands. For this purpose we performed a large study to generate quantitative data about the physical and mental health of DHH individuals. In this paper the term deaf or hard of hearing (DHH) is used for anyone with a hearing loss. The term hard of hearing (HoH) is used for people with a hearing loss who have enough residual hearing to understand some spoken language. The term deaf is used for people without sufficient functional hearing to perceive spoken language. People within this group who have been deaf from a very young age, use a sign language as their first language and who identify themselves as members of the Deaf community are described as Deaf with a capital D. When we refer to the audiological feature deaf, deaf is written with a small d.

Netherlands

On June the 14th 2016 the Dutch government signed the United Nations convention on the rights of persons with disabilities. This is the first legislation in the Netherlands which specifically addresses the rights of DHH people. At the time of this study DHH people had no legislative rights yet concerning specialized facilities other than those based on the principal of equal rights.

There is an extensive network of mental health facilities for DHH people in the Netherlands. In other areas of the Dutch healthcare system facilities for DHH are restricted. Sign language of the Netherlands (NGT) is not recognized as an official language, public information is not translated into NGT and within the healthcare system and society in general, speech-to-text interpreters and NGT interpreters are rarely used in medical situations (17).

Methodology

Here we report on a quantitative assessment of health related quality of life of DHH persons in the Netherlands.

Study group

In this study, which is a part of a larger project, inhabitants of the Netherlands who are DHH and older than 18 years were eligible for entry. The definition "DHH" was based on several self-reported items of hearing functioning. The study was designed to avoid inclusion of people with mental or cognitive issues.

Control group

For comparison with the general population in the Netherlands we used data from the Dutch World Health Organization Quality of Life- Bref scale (WHOQoL-BREF) database (18). Persons were matched for age, sex and level of education.

Participant recruitment

Publicity around the project was generated by articles and announcements on websites, newsletters of patient groups, magazines, national and local newspapers and websites of Deaf clubs and/or organizations for/of DHH people. General information about the study was provided at gatherings of the Deaf community, symposia for DHH people and at medical conferences. In addition, participants were recruited through snowball sampling and newsletters produced by manufacturers of hearing aids.

Participants filled out questionnaires at home on their own computer. People who did not possess enough computer skills to fill out the questionnaire at home could receive assistance at special meetings. Assistance was given by three members of the research team who were trained to provide technical assistance only; no assistance was given with regard to the content.

During the first phase of the study the questionnaire was placed within a secure internet environment. After signing a written consent form, participants received a personal log-in for the questionnaire. During the second phase of the study this was altered because the procedure seemed to hinder participation in the study. Therefore the questionnaire was placed in a secure environment without log-in authorization, enabling people to give online consent instead of written consent. Data were checked to prevent duplications.

Questionnaires

Health related quality of life was assessed using the World Health Organization Quality of Life- Bref scale (WHOQoL-BREF). The WHOQoL-BREF is an internationally standardized, methodologically strong questionnaire. It consists of four subdomains, viz. physical, psychological, social and environmental QoL (19). For this article we will focus on results of the first two mentioned subdomains, which we regard as the medical domains.

The participants also filled out an epidemiological questionnaire which included questions about age, sex, audiological status, audiological features of parents, amplification, socio-economic features, level of education, language skills and demographics. Participants were also asked whether or not they used a sign language (SL), i.c. Sign Language of the Netherlands, and to what extent: mainly NGT, mainly sign supported Dutch (SSD), some NGT and/or SSD alternated by Dutch, or Dutch only. This questionnaire may be obtained from the corresponding author.

Preparation of questionnaires

Questionnaires are reliable only when provided in a person’s first language. For this reason we translated, adapted and tested all our test material into NGT (20). All questionnaires were translated into two versions of NGT according to a forward-backward translation protocol (20). A written version and a sign supported Dutch (SSD) version of the questionnaire were also provided. We used Unipark software to manage the questionnaires in an online environment (21, 22).

Statistical information

This is the first inventory of this kind in the Netherlands. Apart from two Austrian studies, no further comparable international data are available. We based our power calculations on these two Austrian studies that included members of the Deaf community and hard of hearing participants (2, 3). It was calculated that we needed 54 deaf and 189 hard of hearing participants to obtain a power of 0.8 on the WHOQoL-BREF. Our power calculations, database and statistical analysis plan were checked by a statistician prior to executing the study. To minimize the risk of under-powering our study, inclusion of participants was continued for an extra three months after reaching our calculated power. Analyses were performed in accordance with our analysis plan. The outcomes of the DHH groups were compared to those of the general population control group, matched for age, level of education and sex (18).

SPSS software was used to perform statistical analyses. All analyses were performed independently by two members of the team.

Ethics

The research protocol was assessed by a local scientific committee and the regional Leiden University Medical Centre medical ethical committee prior to the start of this study.

Results

The questionnaires were filled out by 274 DHH people. Audiological characteristics based on self- report are shown in Figure 1. Other characteristics and demographics are shown in Table 1.

The audiological functioning of the analysis group was based on self-report; participants had to answer questions about their own perceived hearing status and functional hearing, including questions such as ability to understand speech in a group conversation, understanding speech in a one to one conversation and the degree of hearing loss in dB.

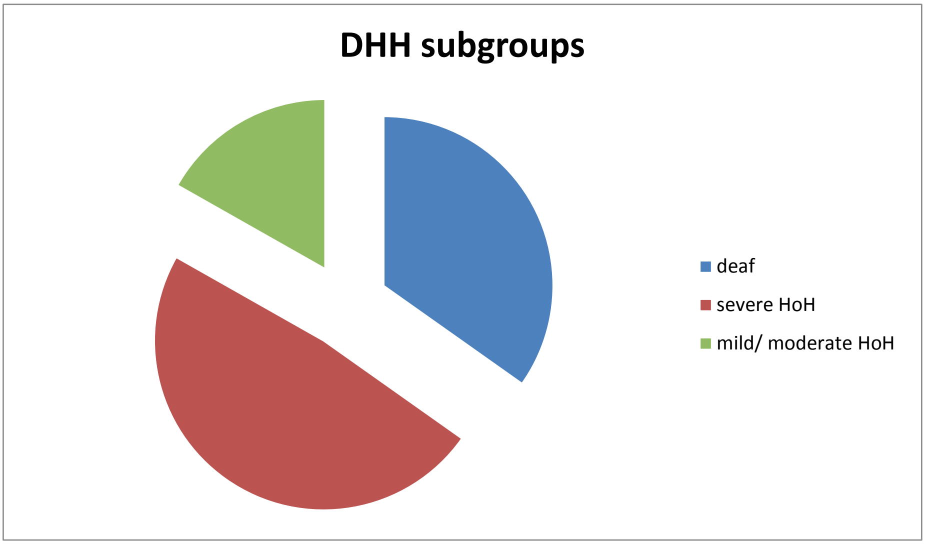

Figure 1: DHH subgroups

We identified seven subcategories on the basis of the age of onset and the amount of the hearing loss as these factors may influence the difficulties and barriers a DHH person may experience (Figure 1). Approximately half of our participants were born DHH or became DHH during childhood or adolescence, 33% of our participants were born DHH or became DHH before the age of five, 20% of the participants became DHH after the age five years but before the age of 21. The other half became DHH at a later age. Less than 5% of our participants were born hard of hearing and became deaf at a later age, or were born mild hard of hearing (MHoH) without significant deterioration during their life.

Table 1: Participant characteristics.

	Deaf	Severe Hard of hearing	Mild Hard of hearing	Control group
Age (derived of year of birth)				Population based control group was matched for age, sex and level of education for all DHH groups separately.
• 18-26	10.1%	4.8%	2.3%	
• 27-36	9.0%	8.9%	2.3%	
• 37- 46	16.9%	12.1%	16.3%	
• 47- 56	17.9%	19.4%	16.3%	
• 57- 66	30.4%	35.4%	30.2%	
• 67- 76	11.2%	16.2%	18.6%	
• 77- 83	4.5%	3.2%	14.0%	
Sex				
• Female	71.7%	71.2%	52.3%	
• Male	25.0%	28.1%	45.5%	
• Unknown	3.3%	0.7%	2.2%	
Level of education				
• Prim./secondary school only	29.9%	13.6%	11.6%	
• Junior secondary technical school	8.9%	9.6%	7.0%	
• Vocational training	26.7%	32.8%	34.9%	
• Bachelor degree	26.7%	34.4%	39.5%	
• Master degree	7.8%	9.6%	7.0%	
Employment	66.7%	53.2%	60.6%	
Having cochlear implant	34.9%	12,2%	2.0%	
Language use				
• Primarily SL	21.8%	0.7%	2,3 %	
• SSD or SSD/SL and spoken language	47.8%	11.3%	6.8%	
• Spoken language only	30.4%	88.0%	90.9%	

In the Netherlands people retired at age 65 up to 2014. Therefore people born before 1945 were excluded from job percentages. (SL= sign language, SSD= sign supported Dutch)

Compared with the general population control group (18) all DHH participants reported highly significant lower (poorer) scores for physical HR-QoL (Table 2a). The hard of hearing group also reported significantly lower (poorer) scores for psychological HR-QoL (Table 2a). Within the subgroup of people who were severely hard of hearing before the age of five years this difference was not significant (Table 2b). People in both the deaf and hard of hearing groups reported significantly lower (poorer) scores for social wellbeing compared to the general population control group.

The group of deaf people, the group of moderately hard of hearing people (MHoH) and the group of people who became severely hard of hearing (SHoH) after the age of five years reported lower (poorer) scores for environmental wellbeing (Tables 2a+b). The same tendency was found in the group with SHoH before the age of five and the whole SHoH group, but these figures are not significant (Tables 2a+2b).

Significant positive correlations were found between both the physical and the psychological QoL and the use of SSD/NGT: more extensive use of supporting signs/SL was related to higher (better) psychological and physical QoL scores (Table 3). A negative correlation was found between the environmental QoL and the use of SSD/NGT but this relationship was not significant (Table 3).

Table 2a: Means and standard deviations (in brackets) for WHOQOL-BREF domain scores.

WHOQOL-BREF scale	Deaf	P Deaf vs GPop	SHOH
Physical	62.13 (17.58)	0.0413x10^{-12} **	55.84 (18.47)
Psychological	68.18 (13.29)	0.479	62.78 (14.11)
Social	67.78 (19.50)	0.036*	65.71 (19.21)
Environmental	68.28 (14.16)	0.0985x10^{-3}**	71.56 (16.62)

Domain scores range from 0 to 100. Higher scores correspond with higher quality of life. Means and standard deviations in the table are unweighted. P values are weighted for sex, age and education level.

Table 2b: Means and standard deviations (in brackets) for WHOQOL-BREF domain scores.

WHOQOL-BREF scale	Deaf before age 5	P Deaf before age 5vs GPop	SHOH before age 5	P SHOH before age 5 vs GPop
Physical	63.85 (17.28)	0.001*	56.40 (18.07)	0.012x 10^{-3}**
Psychological	69.56 (13.61)	0.11	62.94 (13.00)	0.335
Social	69.27 (81.29)	0.56	72.14 (13.15)	0.984
Environmental	68.52 (14.25)	0.002*	73.32 (15.15)	0.200

Domain scores range from 0 to 100. Higher scores correspond with higher quality of life. Means and standard deviations in the table are unweighted. P values are weighted for sex, age and education level.

P SHOH vs GPop	L/MHOH	P MHOH vs GPop
0.0276x10^{-24}**	50.26 (18.00)	2.28x10^{-12}**
0.624x10^{-6}**	59.00 (11.33)	0.285x10^{-6}**
0.2266x10^{-3}**	59.85 (25.10)	0.03*
0.062	69.39 (16.01)	0.04*

The stars in the table indicate the significance of the weighted data compared to hearing controls[19] (*p<0.05, **P<0.001). GPop= General Population control group, SHoH= Severe Hard of Hearing, MHoH= Mild Hard of Hearing

Deaf after age 5	P Deaf after age 5 vs GPop	SHOH after age 5	P SHOH after age 5 vs GPop	L/ MHOH after age 5	P MHOH after age 5 vs GPop
59.62 (17.58)	0,034x 10^{-3}**	56,03 (16,84)	9.064x 10-^{15}**	50,00 (17,05)	1.6708x 10^{-9}**
67.71 (12.38)	0.549	63,40 (11,26)	0.512x 10^{-3}**	59,76 (11,10)	0.077x 10^{-3}**
68.52 (21.56)	0.859	64,67 (18,23)	0.003*	61,18 (22,09)	0.008*
69.23 (13.59)	0.04*	72,28 (14,62)	0.017*	69,57 (15,01)	0.011*

The stars in the table indicate the significance of the weighted data compared to hearing controls[19] (*p<0.05, **P<0.001) GPop= General Population control group, SHoH= Severe Hard of Hearing, MHoH= Mild Hard of Hearing

Table 3: Correlation between WHOQoL-BREF subscales and the use of sign supported Dutch/ Sign language of the Netherlands.

	Extent of using supporting signs/sign language	
	P-value	**R^2**
Physical QoL	0.0008**	0.045
Psychological QoL	0.0047**	0.032
Social QoL	0,1400	0.009
Environmental QoL	0.0623	0.014

The table shows the p values and the determination coefficients (R^2) of the correlation between the use of sign supported Dutch/Sign language of the Netherlands and reported quality of life on the WHOQoL-BREF. (*p<0.05, **P<0.001)

Discussion

Physical health

In this study all three subgroups of DHH people reported significantly lower (poorer) scores for physical wellbeing than the general population control group (Tables 2a+b). This difference was highly significant in the group of people who were DHH from a young age. This outcome is in agreement with other studies (e.g.(2, 3)).

Three possible reasons for the lower scores of people who have been DHH from a young age have been identified. First, barriers to the access of healthcare, as described in the introduction, may have a negative impact on the health of DHH people.

Second, several studies found specific increased health risks among congenital DHH people like increased HIV infection rates, increased prevalence of substance abuse and a higher risk for cardiovascular disease and metabolic syndrome (4, 23-31). Third, it may be a consequence of the fact that they form a special subgroup with respect to the cause of their DHH. Congenital DHH may be the result of genetic or congenital disorders, accompanied by lifelong physical and mental sequelae. The incidence of these disabilities in DHH children is estimated to range from 25-34% (32).

This study is part of a larger research project. The aim of this project is to study the first two possible causes for lower HRQoL-scores in DHH people. Therefore people with congenital DHH and severe additional disabilities were excluded by the design of this study, but some degree of DHH related disabilities cannot completely be excluded.

Although we cannot conclude from this study that barriers to the access of healthcare and group specific healthcare risks are the main cause of the lower physical quality of life of congenital DHH people, it seems clear that they can have a negative influence on their health and should be removed as far as possible.

People who became DHH at a later age may experience barriers to healthcare access as well.

Next to this they may have comorbidities related to the cause of their DHH. The people with comorbidities related to the cause of their DHH were not excluded by design of the study, therefore we cannot make any statements about the impact of the different possible causes for lower physical HRQoL among people who became DHH at a later age.

Psychological health

Scores for psychological health were higher (better) in the deaf subgroups than in the hard of hearing subgroups: In contrast to other studies, deaf participants in the Netherlands did not report more psychological problems than the control group.

We do not think that this is caused by methodological issues such as choice of instrument or participant recruitment. The WHOQoL-BREF was especially chosen because of its ability to reveal internalizing problems because of their higher prevalence in DHH people according to the literature. As some of the meetings we organized were located close to a psychiatric facility for DHH people, and several of their patients participated in this study, we have no reason to believe that psychologically healthy people were overrepresented in our sample.

A possible explanation for the better scores for psychological wellbeing of deaf people than of hard of hearing people may lie in the provision of specific mental healthcare facilities for deaf people in the Netherlands. No research has been done to evaluate the effect of specialized facilities, but it is possible that the extensive availability of these services may have influenced the finding of a better perceived psychological quality of life in deaf people, compared to the hard of hearing participants who have limited access to specialized healthcare facilities.

Another explanation may come from the fact that, until relatively recently, children with mild hearing loss were not diagnosed at a young age. They started school without knowing about their hearing loss and were often wrongly accused of being stupid or unwilling to listen. This may have lowered their self-image and their psychological QoL accordingly.

We found that the psychological health of Deaf people in our study was better than that reported in studies from other countries (3). This may be the result of an extensive network of facilities for mental health support for deaf people in the Netherlands.

The mode of language and Deaf culture on health related quality of life

There are many debates in the literature and in (clinical) practice concerning which subgroups of DHH people can benefit from the use of sign language, and to what amount. We found a significantly positive relationship between physical and psychological health, and the use of sign language and/or supporting signs. It appears that the protective effects of using as many modes of communication as possible is stronger than the possible negative effects of learning a language only partially. We did not find a minimal required ability to use sign language or supporting signs for these positive effects, the effect was present among all DHH subgroups. The relationship was continuous: the more sign (language) a person uses, the higher the score on the QoL scales.

Strengths and limitations

Unintentional selection of participants may influence the outcome of studies. We attempted to minimize this by making the study design as undemanding as possible, and by trying to reach a broad profile of the group we intended to study, e.g. by using newsletters of a hearing aid manufacturer instead of addressing patient groups only. Although there was an overrepresentation of females in our study group (two-thirds of the participants were female), the number of male participants was high enough to perform a reliable statistical correction for sex.

A possible bias in the classification of the DHH group is that all audiological parameters are based on self-report. This method was chosen because full audiological examinations would be expensive and time consuming for the participants, whereas this would probably not provide much additional information on hearing function. By enabling participants to fill out the questionnaires at home in their own time, the threshold for participation was lowered.

With respect to age of onset and degree of hearing loss, the study population seems to be a representative sample of the Dutch DHH even though relatively few people with a mild, non-progressive DHH from birth are included.

Implications for the future

Both deaf and hard of hearing people, regardless of the age of onset, report poorer physical health related quality of life than their hearing peers. More knowledge and awareness is needed concerning the specific health problems of DHH people. It is important that DHH people are recognized as patients who require special attention.

We think it is necessary to create more awareness among healthcare workers and DHH people themselves about the possible healthcare barriers they may encounter and experience, and - more importantly - about how to avoid or overcome these barriers. The development of healthcare facilities to support DHH people and their healthcare workers, (e.g. the network of specialized mental health facilities in the Netherlands) may be effective but the effects of such facilities should be monitored and evaluated (12).

Conclusion

DHH people experience significantly more physical and psychological difficulties than people in the control group. More extensive use of sign language is related to a reported better health related quality of life. Scores for psychological health were higher (better) in the deaf subgroups than in the hard of hearing subgroups; in contrast to results from other studies, deaf participants in the Netherlands did not report more psychological problems than the control group.

More awareness and knowledge concerning the specific health problems of DHH people is necessary to enable appropriate and adequate healthcare provisions. DHH people and healthcare workers should be alert for co-morbidities and barriers to access of healthcare, be educated in how to recognize and deal with them, and when to consult an expert, specialized services or communication assistance (e.g. text-to-speech- interpreter or sign language interpreter).

Recognizing DHH people as a patient group requiring special attention is the first step towards improving their health.

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