



An Excluded Minority, Without Access and Knowledge to Health Services

Health Deafinitions' Response to *The Way Forward*



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Introduction

Since 2007 we have been consulting directly with the Deaf community throughout England to understand how they access healthcare, conduct self-care, and the general state of the community's health knowledge. It has become clear to us that Deaf patients and the NHS itself would be transformed by the proper utilization of health education in fluent BSL, using visual and culturally relevant presentations. As a Deaf led and staffed organization we have been involving the community at every stage in developing the health education we seek to provide to Deaf patients.

As such we welcome this consultation and the work of Healthwatch as a consumer advocate, recognizing that, fundamentally, patients are rights holders as citizens and NHS service-users. *The Way Forward* articulates some key developments and hope for future action against the health inequalities faced by the Deaf community. Both rights and responsibilities, and the implementation strategy, highlight the experiences and needs of the Deaf community as an excluded minority missing life-saving access and knowledge.

Deaf patients lack access to full NHS care because of insufficient recognition of their distinct identity as a cultural and linguistic group. As such their human rights to equality and "standard of living adequate for the health and well-being" are effectually denied.ⁱ However, the lack of knowledge is the core limitation to Deaf health, and subsequently perpetuates Deaf health inequalities. Absent understandings of self-care, long-term conditions, patient responsibilities, and how the NHS works culminates in poor health and lower life expectancy. Current material available to Deaf patients does not sufficiently fill these holes. Entitled to education "without distinction of ... language", indigenous British Sign Language users have little access to the knowledge required to avoid some of the worst mortality rates in the country.ⁱⁱ

These issues and on-going challenges are certainly not unknown to Healthwatch. The recent Healthwatch York report on Deaf health issues in the Vale of York CCG indicates the localized impact of this national trend. Frequent news reports about Deaf patients throughout the country being denied access because of poor communication accommodations or simple discrimination demonstrate this trend.ⁱⁱⁱ

This response provides Health Deafinitions' feedback to *The Way Forward* and offers further commentary on the crisis of Deaf health inequalities in England with our unique perspective as a Deaf charity that deals first hand in health education and community partnership.

Strategy, Vision and Mission

The mission and vision of Healthwatch are highly commendable, however, in order to fulfill these aspirations for Deaf consumers, a specific strategy should be developed. As a marginalized linguistic and cultural group, this community needs the statutory power of Healthwatch to further expose this health inequality crisis.

Identification

Nationally, Healthwatch should implement the boldness and scope of the Healthwatch York report. This research reflects our own findings through a 2009 Health Needs Assessment (HNA) in Wakefield with the then Wakefield PCT about Deaf patient experience, and the statements we have gathered from Deaf local communities since 2007: Deaf patients' needs are not met through current interpreting services and demand improvements to their access.^{iv}

A concise Deaf strategy review would identify this national trend that has been attested to locally and produce evidence to substantiate the change required in terms of access and education. Healthwatch would then be able to present these findings to the government on behalf of the Deaf consumers it represents and push for better access and information in fluent BSL.

Another alarming national aspect of Deaf health inequalities is the continual, and exclusive, reliance on BSL interpreters. This is a result of traditional views of d/Deafness as disability, even among Deaf people themselves, that interpreters are needed as an intervening aid to understanding, and that they should be more available and better qualified. This fails to recognize that interpreters do not overcome the lack of health knowledge, and the given the correct format Deaf patients can learn more about their health and well-being.

Other public services, such as the Police and court system, legally require interpreters to have specific terminology certification; however, this does not exist in the health profession. So-called 'cowboy' interpreters are able to show-up to GP appointments and convey through poor signing to Deaf patients medical terms and diagnosis, who themselves already have a profound dearth of health knowledge. This scenario only worsens as patients are forced to take family members as interpreters because of a lack of professional interpreter provision, or the latter simply not arriving at the appointment.

Improvements to Deaf health *education* through fluent BSL, not translated English, information would greatly aid the development and better regulation of the health and social care Deaf interpreter industry. Empowering patients is a frequent banner of the

NHS; it should be made a reality to those whose rights to equality and education are not fully recognized.

Development

Healthwatch itself must also be considerate of Deaf linguistic and cultural difference and offer more than Easy Read and English translated material if it wishes to truly reach the Deaf community, particularly its grassroots members who live outside of the hearing world and have an average English literacy of a nine-year-old.

Recently we communicated with Andy Payne, Healthwatch England Development Officer, regarding these issues of access and knowledge, who then referred us to John Conisdine. We put to them the following regarding the explanatory “BSL” video about what Healthwatch is and its role as a consumer champion.

“If I may draw your attention to an example of the kinds of language and cultural barriers faced by Deaf patients. Recently posted on the Healthwatch site was an introductory video entitled, “What is the Healthwatch Network?” Although this seven-minute piece utilises an experienced BSL-user, it is apparent to us, as a Deaf-led organization, that there are some reasons why this will not reach the intended Deaf audience. Having asked a number of Deaf colleagues to watch it, representing the grassroots Deaf community, these are a few of their comments.

- *The signer switches between Sign Supported English (SSE) and BSL at several points, limiting the culturally appropriate nature of the presentation.*
- *Given the fast-paced nature of the translation this makes it very hard to follow for Deaf people who typify the community’s average literacy of a nine-year-old, to whom the subtitles would not have helped.*
- *Much of the institutional language and reference to committees and bodies connected to the NHS and government functions were confusing and nonsensical, and lacked proper context for a Deaf person.*
- *How Healthwatch related to these bodies was also unclear, in fact, many of our Deaf colleagues had not heard of Healthwatch, nor had any grasp of what you do, and felt this was more a presentation for highly professional or intellectual individuals than the average Deaf person.*
- *Consequently, this presentation appeared to be bereft of comprehensible information about Healthwatch that a grassroots Deaf person could understand in an appropriate format, and missing crucial, engaging visuals.”^x*

Several issues were raised here, to which we have yet to have a serious response. It is clear that the information offered to Deaf consumers by Healthwatch does not reach those most in need of representation. These are those most vulnerable to being at high-risk for Cardio-Vascular Disease and long-term conditions such as diabetes due to the lack of health education in their own language. We offer a service that provides custom-made health education resources for Deaf people in the form of informational video presentations that are community developed and consulted, culturally applicable, and in fluent BSL, not translated English.

Promotion, Design and Delivery

During the Wakefield HNA we found what 92% of d/Deaf respondents wanted most from their health services was information in the right format.

“The health service with the most ‘very important’ ratings was “Information that will help me live healthily” at 72% (36) of those surveyed... with “Information in the right format that explains NHS services” at a very closer third with only one less point. But if adding the ‘important’ and ‘very important’ selections together, then the “Information in the right format” comes highest at 92% with 46 people rating it that highly!”^{vi}

Incorporating these findings into Healthwatch’s future is crucial if it is to reach the ‘grassroots’ elements of England’s Deaf population. It is this vast majority of the Deaf community that typifies the above low English literacy rate. The concept of having rights is readily taken to by Deaf people, however, grassroots Deaf patients need health education that uses fluent BSL to lay out what responsibilities correlate with their rights as consumers of health services.

Our service can help bridge this gap and extend Healthwatch’s remit to the Deaf community it should represent. Visual, fluent BSL information about Healthwatch would educate the Deaf community about its role and therefore make their services more accessible to this excluded minority.

Rights and Responsibilities

What do you think about our draft rights?

The rights drafted in the Annual Report 2012/13 represent some drastically needed improvements for the Deaf community. The catalyst to the realization of these rights is effective communication, particularly facilitating Deaf voices on development and implementation: communication that moves beyond the reliance on second or third-hand translations through interpreters. This would make the right “to be involved” essential to the Deaf community, in terms of both entitlement and responsibility. Due to the lack of knowledge and past negative experiences many do not feel confident enough to be more involved: successful outreach to Deaf patients and subsequent involvement will only come when paired with empowerment. We believe that the latter comes with education.

This collection of rights, as a summary of the NHS Constitution’s own list, does seem to miss out on the below point on adapting to local communities,

“You have the right to expect your NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary, and in the case of public health services commissioned by local authorities, to take steps to improve the health of the local community.”^{vii}

Does Healthwatch’s approach to rights and responsibilities understand the importance of the Deaf community’s need for health education and the specific requirements that a cultural and linguistic group will have? This community must have consumer rights to be addressed and accommodated on its own terms.

What are your experiences of these rights, and/or those of your family, friends, or people you represent?

Generally speaking, the Deaf people we have consulted with over the years have stated a clear lack of trust in NHS services and personnel, especially when it comes to appropriate and clear communication, with numerous examples of barriers and not understanding their own health. Our own partnership with the old Wakefield PCT demonstrated that few Deaf patients felt acknowledged and even at times respected by NHS staff.

This community has seen little improvement in terms of access, safe, dignified and quality service, and being listened to. However, above all, we have found that the Deaf community is looking for education not just improved interpreting. They have demanded visual, fluent BSL education; this is why Health Deafinitions is pursuing this type of learning a reality for the community.

Would these experiences have improved if you knew about these rights? If so, how?

Knowing about these rights alone will not have made a difference, as Deaf patients would need educating about the system of statutory and consumer rights: how would they bring grievances forward, and to whom; what would be the process of response? By and large many Deaf people, because of a lack of understanding and confidence in the hearing world, would consider these as a non-departure from the status quo of current health inequalities.

What does responsible and irresponsible use of health and care services look like?

Responsible use of health care looks like educated patients knowing how the basic exchange of rights and responsibilities work, and what this means in real terms for achieving access to healthcare. Statistically Deaf patients contribute significantly to high 'Did Not Attend' rates and inappropriate use of A&E services.^{viii} Having the appearance of irresponsibility, these trends are the product of lack of an appropriate treatment of Deaf patients. Responsible users of health and social services would be Deaf people who understand the system and utilize the services appropriately, choosing the correct service to contact and attend with informed minds that can aid in diagnosis and any support given.

How do you think we should work with the public and organisations to promote people's rights and the responsible use of health and care services?

Consultations should be held that provide workshop environments for Deaf patients to understand the Healthwatch representation process, and what consumer advocacy means for them as patients. These must be made available, unequivocally, in visual, fluent BSL – not information simply interpreted from English, lacking the cultural and linguistic nuances. Videos that accompany any such conferencing or workshop would be key to success in the Deaf community.

Again the issue of involvement is paramount. Although listed in the Healthwatch draft rights, the "right to be involved" does not seem to be adequately reflected in the NHS commissioning, development and provision of services, as stated in the NHS Constitution,

"You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services"^{ix}

Realizing this right of Deaf patients would encourage involvement that is empowering and transforms current issues surrounding absence of access and knowledge that produces Deaf health inequalities. Deaf patients actually being involved in commissioning and developing their own communication methods and education in the health sector would save money for the NHS, increase life expectancy, improve life for those with long-term conditions, and affect positive patient experiences. This is what Health Deafinitions offers.

What else do you want to tell us about rights and responsibilities in a health and care context?

BSL is the first language of over 150,000 Deaf patients in England, and their human right to linguistic identity must be fundamental to any furthering of consumer rights and responsibilities.^x This entails that interpreted information does not instantly resolve the language, knowledge and cultural barriers encountered by Deaf people in health and social care situations. Adequate health education and an understanding of rights and responsibilities must be provided to the community in fluent BSL, in a culturally applicable manner.

A Rights Report Card

To offer further context to the ground that must be covered to achieve consumer rights and responsibilities for Deaf patients the following is a sample of occurrences and research that describe the current state of healthcare for Deaf patients. Included are references to our own research and the recent Healthwatch York report.

<p>Essential services</p>	<p>Emergency services are notoriously hard for Deaf patients to access due to the unavailability of interpreters, “I was rushed to the hospital by an ambulance. Doctors were surrounding me without an interpreter. Doctors were talking to each other and I couldn’t follow what they’re saying.... My wife tried to converse with them, we both couldn’t follow them. It was a complete communication breakdown and it was really awful. I had to wait for a long time to get an interpreter. It was 3 or 4 hours surviving in this hospital.... Doctors had left long ago and then the interpreter arrived. I asked the nurse, via interpreter, what the doctors were saying, but the nurse couldn’t comment, as it is had to be from the doctors directly. This was a very poor service, especially in emergencies. It is a common problem” (Deaf Male, Health Deafinitions Deaf club consultation, 2008).</p>	<p>Access</p>	<p>NHA Wakefield report found that 38% felt they were not given enough time in appointments, and 50% felt they needed more time (Health Definitions Health Needs Assessment, Wakefield PCT, 2009). “You know health leaflets are distributed out to people with formal English, it is no good to me. This is because there is too much written English and very few pictures on the leaflets. (Visual information) would lead me to be better and more confident person with my GP next time because I would know what I am talking about. This is due to that visual information beforehand. Whereas right now if I never saw the visual information, I would remain unsure of what to tell my GP about my actual knowledge of my health and my conditions because I don’t have much information or knowledge about it. My GP tells me about my conditions as well as the dos and don’ts, I would say yeah, yeah or thumbs up, but in ignorance” (Deaf female, Health Deafinitions Deaf club consultation, 2008).</p>
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<p>A safe, dignified and quality service</p>	<p>Many Deaf patients walk away from consultations with a medical professional without a clear understanding of what happened, or any life-saving instruction that might have been given, “My Doctor told me about taking the medication, but I couldn’t read his mouth pattern so I didn’t understand what he was saying. I just nodded, pretending I understand him. But when I got home with my prescription, I admit I began to feel unsure of the medication because I don’t know what he’s said to me – what benefit the medication has, the purpose of it and what it does to make me better. The doctor tells me very short information but I don’t fully understand it. It could be the wrong medication, and maybe make me worse because I might have given wrong information. That could be dangerous if I’m being misdiagnosed. It could lead to health complications and I may worsen or die from wrong treatment. To have proper language that is accessible to my needs is so vital” (Female, Health Definitions Deaf Club consultation, 2010). “Deaf people are victims of cuts. My Deaf father-in-law died in hospital – I was his interpreter for 48 hours with no sleep” (Healthwatch York, 2013).</p>	<p>Information and education</p>	<p>Interpreters are not sufficient or effective themselves in conveying information to Deaf patients, “I usually use my mother but she has a health problem I don’t use her as much I end up stuck because I don’t have access to interpreters” (Deaf female, NHS England Accessible Information Survey feedback 2014). Information currently provided does not amount to good education for Deaf patients, “They give me another format but I won’t use it because I don’t understand it. I don’t trust them or the other format. I really don’t trust them. The information is really not very clear.... Nothing, I need in-depth information with better visual aids” (Deaf Male, NHS England Accessible Information survey feedback, 2014). “The health service with the most ‘very important’ ratings was “Information that will help me live healthily” at 72% (36) of those surveyed... with “Information in the right format that explains NHS services” at a very closer third with only one less point. But if adding the ‘important’ and ‘very important’ selections together, then the “Information in the right format” comes highest at 92% with 46 people rating it that highly!” (Health Deafinitions HNA Wakefield PCT, 2009).</p>
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<p style="text-align: center;">To choose</p>	<p>Deaf people from varied backgrounds with the confidence to do so have asked for more information in BSL, as their first language choice, but are not consistently provided with this option, “I feel that for any forms, there should be a note stating that there is a BSL format available, also on waiting list, or medical records, there should be note in bold or highlighting, stating the need of language-BSL. This is because it is very easy for the staff to assume I am a hearing person. If there are a list of language preferences, and if BSL is mentioned, it would take a lot of weight off my shoulders knowing I can be stress-free in communication. Being comfortable is what counts” (Male, NHS England Accessible Information Survey, 2014).</p>	<p style="text-align: center;">To be listened to</p>	<p>Many Deaf patients find a record of their Deafness is not made, or acknowledged by health professionals. “My sister is a doctor and are both diabetic. She came to see the specialist with me and the doctor was explaining things to me and he just said, “Well, it’s for life”. I was really upset. My sister wasn’t happy, she told him that I was deaf and that he needed to make sure I understood the information about it. He told her that he was a doctor, the professional, and it had nothing to do with her; but she said it was shameful that he wasn’t explaining things properly for his patient” (Deaf male, Health Deafinitions Deaf club consultation, 2009). “I went with my husband to the GP – we are both Deaf, and he had lots of health problems. We were told to go and wait upstairs. Someone came in and said ‘Come on, come on’. It was embarrassing. When we got in to the surgery the GP said ‘Oh, Deaf’. The doctor got angry about it. We got sent back downstairs. He called my husband deaf and dumb, and was very rude” (Healthwatch York report, 2013).</p>
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<p>To be involved</p>	<p>Communication and knowledge barriers prevent acceptable levels of self-care occurring within the Deaf community, “I find it difficult to communicate. If a hearing doctor is talking, or the interpreter is talking to the doctor, I never understand what is going on. I do not fully comprehend the information. I never fully understand. I still have some misunderstandings” (Male, NHS England Accessible Information Survey, 2014).</p>	<p>To live in a healthy environment</p>	<p>Because Deaf people lack health knowledge they are less able to create healthy environments for themselves. As such, Deaf people are at high risk for CVD, “(Deaf) language barriers contribute to CVD risk within this group.... The risk of CVD is also likely to be higher in Deaf people of the UK” (Patel et al, <i>Cardiology Research and Practice</i>, 2011).</p> <p>Outside of the available care of the NHS many Deaf people are not aware of care available to them, and likewise do not have regular contact with a GP. The following is one of many accounts of a Deaf person dying prematurely as a result of insufficient access to health and social services, “Due to communication problems within the hearing world he became adversely affected with stress, irritability never wanting to work amongst the hearing due to perceived undue pressure in a work place. After about 5-6 years of zero communication with him, I met him again, and he had spiralled into deep mental instability, lost his usual physical features. Sadly, the next news we heard about him was that he was dead. It dawned on us what risk/impact of settling into yourself when you have any form of problem especially health-wise. We also recognized that the absence of adequate resources and support played a part in this tragedy. Although, we have not been informed of actual cause of his demise, all fingers point to his ability not to find suitable treatment and support as needed was a factor and that the awareness, information and knowledge of personal care and health matters is undeniably paramount to ones well-being. His death at the early age of 41 has been a wake-up call to us all within the Deaf community.”</p>
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Deaf Health Inequalities in York

The gauntlet was firmly laid at the feet of the Vale of York CCG by the Healthwatch York report. As this is so recent it is perhaps unreasonable to expect any concrete action to have been taken by local government or the CCG itself as of yet. However, this report and its implicit challenge will serve as a litmus test for both Healthwatch and the reformed NHS on Deaf health inequalities. The section poses a series of questions to further this important moment for change and to encourage Healthwatch to not let the opportunity in the York area pass-by.

- What statutory response process is being followed after this report?
- What key stakeholders does Healthwatch work with nationally on Deaf health? Do they incorporate the grassroots Deaf community?
- This report highlights issues that we have been identifying since 2007, how is the following status quo going to be left to the past? “There was frustration and anger that these issues have been raised through a range of channels for a number of years with no subsequent action.”
- As NHS England Primary Care North Yorkshire area team confirmed that it is GPs’ responsibility to ensure interpreters are in place, what kind of follow-up will take place, and will there be discussion about GPs’ essential responsibility to provide health education to Deaf patients?
- Why does the Vale of York CCG Equality and Strategy Implementation Plan 2013-2017 not make reference to Deaf people as a protected or at-risk group? What changes will be made to this document following the Healthwatch report?
- Will the CCG recognise the “human cost” and “significant litigation risk” with their own research and investigation?
- Generally, the experiences of Deaf patients indicated that they were not being listened to, and especially not asked about what communication needs they had, what safeguards will be introduced by the CCG and the council to prevent occurrences from continuing?^{xi}

Succinctly the report is concluded with the following indictment,

“Putting Deaf people at a disadvantage when accessing health and social care services could also be seen as a failure to comply with the Human Rights Act 1998 - in particular the right to be free of inhumane or degrading treatment (article 3) and the right to a personal and family life (article 8).”^{xii}

This strong declaration will appear trite if action is not pushed for by Healthwatch England, and Deaf involvement for improved access and knowledge will be merely aspirations repeated to a continually excluded minority. The recommendations seem only to address some short-term access issues, and lack a clear vision for long-term transformation beyond offering more interpreter services – which does not change health inequalities faced by Deaf people.

Conclusion

As the situation stands, and the past attests, Deaf patients are significantly disadvantaged, and are disproportionately burdened with health inequalities. Dispersed throughout England these patients are not sufficiently represented and lack the social confidence and cohesion to raise these concerns either singularly or collectively.

The British Society for Mental Health and Deafness has stated the following regarding Deaf people utilizing the Deprivation Index,

“If Deaf people all lived in one place their community would be at the top of the Deprivation Index and would qualify for significant government funding to put right the damage caused by decades of National Institutional Discrimination across Government Departments. Instead, as a dispersed cultural/linguistic indigenous minority, literally without a voice, they are ignored. “Three in a Thousand” does not seem to exist; statistics below 1% are routinely suppressed for convenience, leaving over 100,000 deaf Adults without access to appropriate services.”^{xiii}

Healthwatch is empowered with legal powers to force dialogue about health services, and is therefore obligated to raise Deaf health inequalities as serious examples of breaches of consumer rights and a profound opportunity to improve the access to and quality of care for Deaf patients. The Healthwatch York report could be a catalyst to this long needed change.

Health Deafinitions, as a consequence of our community roots and consultations, offers an opportunity to provide health education that would empower patients with access and knowledge, making their status as an excluded minority a thing of the past.

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ⁱ *Universal Declaration of Human Rights*, articles 1, 2, 25, accessible at <http://www.un.org/en/documents/udhr/>

ⁱⁱ Lisa M. Harmer, "Health care delivery and deaf people: practice, problems, and recommendations for change," *Journal of Deaf Studies and Deaf Education* 4, ed. 2 Spring (1999): 76-77, accessible at <http://jdsde.oxfordjournals.org/content/4/2/73.full.pdf>

ⁱⁱⁱ Consider the following recent stories "Deaf couple angry with hospital over lack of interpreter during birth of son," *The Guardian*, accessible at <http://www.theguardian.com/society/2014/jan/19/deaf-couple-lack-interpreter-birth-university-college-hospital-london>, "Round-up: The worst deaf health horror stories," *The Limping Chicken*, accessible at <http://limpingchicken.com/2013/12/10/round-up-the-worst-deaf-health-horror-stories/>

^{iv} Health Deafinitions, *Health needs assessment of the Deaf and Partially Deaf Community Report*, NHS Wakefield District, October 2009, accessible at <http://www.hcp.healthdeafinitions.org/health-needs-assessment-report.html>

^v The video can be accessed at <https://www.youtube.com/watch?v=MDorlI0zkWk#t=228>

^{vi} Health Deafinitions, p15.

^{vii} NHS Constitution, available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf

^{viii} RNID, *A simple cure: a national report into deaf and hard of hearing people's experiences of the National Health Service*, available at <http://www.stah.org/Portals/0/docs/RNID%20A%20Simple%20Cure.pdf>

^{ix} NHS Constitution.

^x The BDA surveyed figure of 156,000 Deaf BSL-users combines their own research and other authoritative polls, see <http://www.bda.org.uk/News/108>. Many in the Deaf community feel that the number is even higher, approaching 250,000.

^{xi} Healthwatch York, *Access to health and social care services for Deaf people*, p9 and 14, available at <http://www.healthwatchyork.co.uk/wp-content/uploads/2013/12/Healthwatch-York-report-on-access-to-services-for-deaf-people.pdf>

^{xii} Healthwatch York, p14.

^{xiii} *British Mental Health and Deafness Association*, "Deaf people's mental wellbeing put at risk by lack of services," available at <http://www.bsmhd.org.uk/news0710.htm>