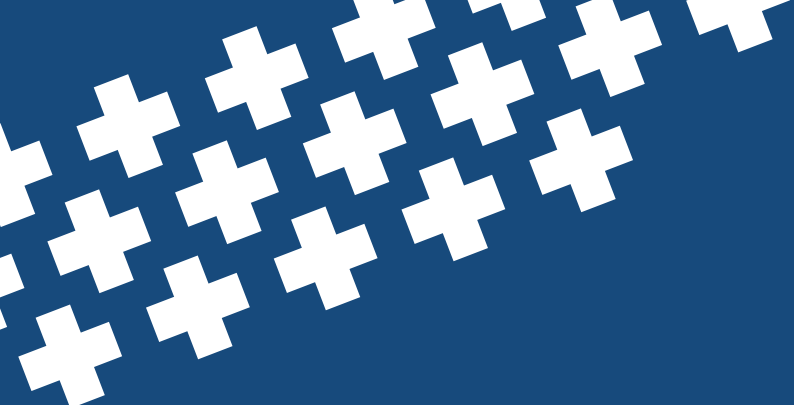




# my life my health

Deaf Young People's  
Experiences of Health Services –  
A closer look





# “What we want is to be treated as equals”

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# Executive Summary

## Background

Young people have a right to high quality, accessible health care. However, research has found that young people often have negative experiences in this area and, that when children are from vulnerable groups, these experiences can be amplified because services are not set up to meet their specific needs<sup>1</sup>.

Effective management of young people's health will result in improved outcomes for them as adults<sup>2</sup>. But young people with long term conditions frequently drop out of health services during the transition period between children's and adults' services, something that can have serious consequences for the individual<sup>3</sup>. It is therefore no surprise that deaf young people can be at risk of poorer health outcomes as adults<sup>4</sup> and that this could potentially have been avoided with regular contact and health promotion.

## Summary of report

This report was produced by the National Deaf Children's Society (NDCS) and its Young People's Advisory Board (YAB), a group of 17 deaf teenagers recruited from all over the UK. They work to identify and address issues that affect deaf children and young people and chose healthcare as a key issue that they wanted to explore.

The report is based on the views of more than 200 deaf children and young people, gathered through focus groups and a survey. During the course of the consultation, many deaf young people shared positive experiences and the report contains some examples of this good practice. However, others said that lack of accessible services meant they struggled to understand what was happening to them or were forced to rely on their families to access basic information about their own health, even when they were long into adulthood.

By sharing some of these experiences, the Young People's Advisory Board hopes to generate discussions and changes in practice that will improve the accessibility of local health services for deaf children and young people.

Following the consultation they have identified three key areas where improvements are needed.

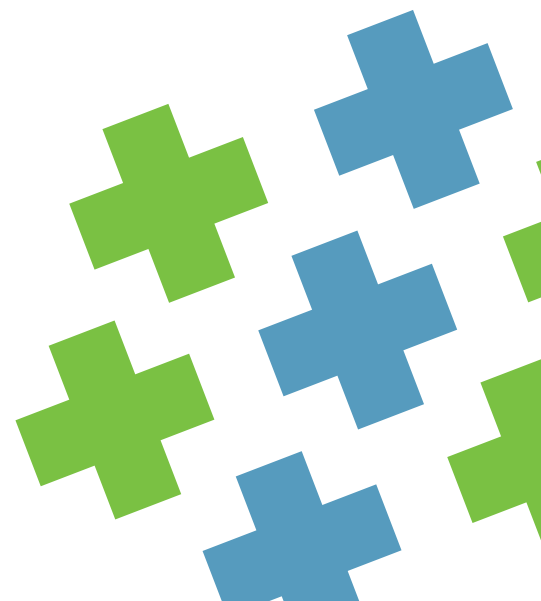
The purpose of this report is to examine the particular barriers that deaf children and young people encounter when using health services, and to outline positive steps that will ensure they are no longer at a disadvantage when compared with their hearing peers.

<sup>1</sup> NCB (2012) Listening to children's views on health provision.

<sup>2</sup> Adolescent health in the UK today: Update 2012. Association for Young People's Health

<sup>3</sup> Blum R, Garell D, Hodgman C, et al. (1993) Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health* 14:570-576. & Transition: getting it right for young people, DH & DfES 2006

<sup>4</sup> For example, studies, cited in Department of Health and National Institute of Mental Health (2005). *Towards Equity and Access* have found that 40% of deaf children suffer mental health problems compared to 25% of hearing children.



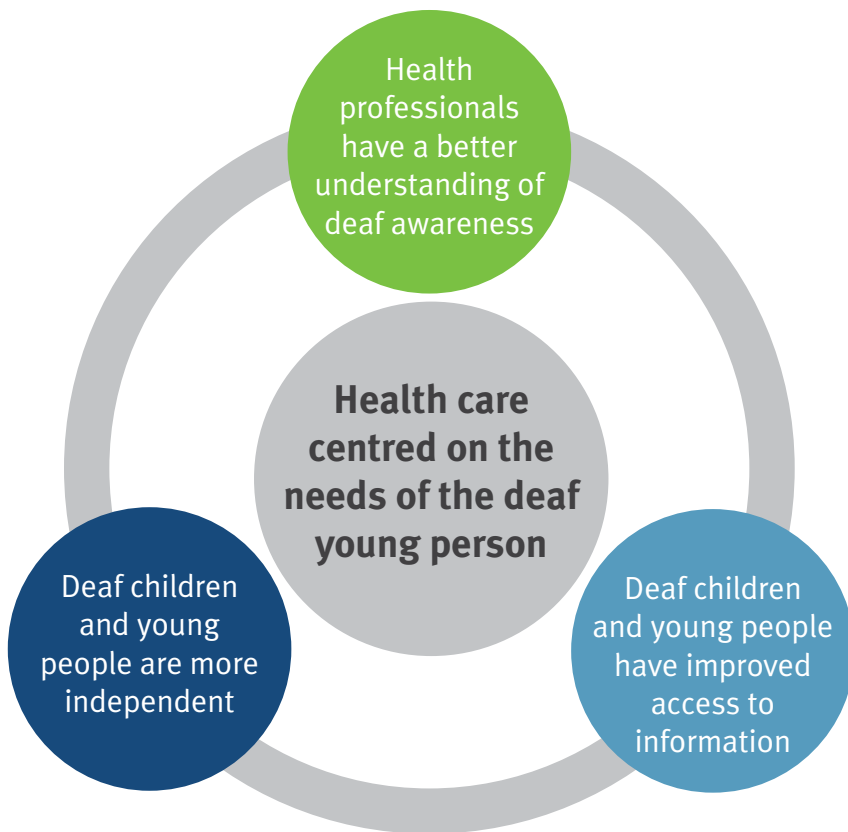
**Better deaf awareness:** healthcare professionals need to become more aware of the needs of deaf children and the barriers they face so that health services become more deaf friendly and accessible.

**Improved access to information:** health professionals need to ensure deaf children and young people understand the information provided about their own health.

**Encouraging independence:** deaf young people need to be supported to become more independent in relation to their own health care.

A summary of key recommendations is shown on page 5.

Professionals, parents and young people themselves all have a role in ensuring that deaf young people receive the best possible health services. Simple steps in each of these three areas can have a huge impact on the services deaf children and young people receive. For example, if GPs are more deaf aware, deaf young people will have greater access to information, will be more independent and will therefore be empowered to explain to a GP how their needs can be met.



To accompany this report NDCS has created a range of resources to support healthcare professionals, parents and deaf young people to address the issues that deaf young people have told us are important. NDCS will work with other organisations to ensure that deaf children and young people’s voices are heard and acted upon. Resources can be found here: [www.ndcs.org.uk/mylifemyhealth](http://www.ndcs.org.uk/mylifemyhealth).

**What does NDCS mean by the term ‘deaf’?**  
In this report, the term deaf is used to refer to all types of hearing loss from mild to profound. The term includes deafness in one ear or temporary deafness such as glue ear. It includes all children and young people that health professionals may identify as having a ‘hearing loss’.

# ReCommendations

## Ensuring better deaf awareness

- All health professionals should complete basic deaf awareness training as part of their induction. Health professionals should also undergo refresher training where a deaf young person starts to come into regular contact with them.
- Medical records should make it clear that a child or young person is deaf and what their communication preferences are.
- Deaf awareness training should ensure health professionals are aware of the simple things they can do to improve communication such as ensuring eye contact, good lighting and avoiding speaking too quickly.
- All health settings should have visual alert systems or pagers in place so that deaf children and young people know when it is their turn.
- A range of systems should be in place to allow deaf children and young people to book appointments so that they don't have to make a telephone call or rely on family members. This should include email and text messages.

## Improving access to health information

- Deaf children and young people communicate in a range of different ways. Health professionals should ask what their communication preferences are and ensure this is recorded in their records.
- Health professionals should ensure that information provided to deaf children and young people is clear, easy to understand and free of jargon. Consideration should be given to presenting information visually through leaflets and video clips.
- Health professionals must break information down into chunks so that deaf children and young people have time to take it in and understand it. Health professionals should check the young person's understanding throughout and leave extra time to explain any difficult concepts.
- It is the responsibility of health professionals to ensure that communication support is in place and booked before a deaf child or young person attends an appointment. It should never be assumed that family members will provide communication support.
- Deaf children and young people need more information about communication support and the role of interpreters. They should be empowered to exercise their rights in this area, as well as their rights to good health care.

## Encouraging independence

- Ensuring basic deaf awareness is in place and that information given is accessible are both vital preconditions to independence.
- As deaf young people get older, health professionals must always talk to deaf young people directly, and not to their parents or interpreters.
- Deaf children and young people and their families need support to work out when and how they will begin their journey to independence. Health Professionals and parents have a role to play in encouraging deaf young people to take these steps to independence.
- Transition to adult services must be carried out in consultation with the young person and their family to ensure that deaf young people are ready and confident about the move.
- Deaf young people must be empowered, supported and encouraged to clarify, ask questions and make sure they understand. They should be provided with information about the importance of becoming independent in their health care and clear on the steps they can take themselves to progress this.

# Foreword from the Young People's Advisory Board

Deafness. It's just a small word, but can be life changing. Throughout their lives, deaf children will often come to face problems and challenges. This may be at home, school, work, clubs or anything else. The amount of difficulties can be huge, but NDCS aims to change that. This then brings in another problem, what do deaf kids really need help with?

This simple question has led to the birth of the Young People's Advisory Board (YAB), a group of 17 deaf teenagers recruited from all over the UK. Our task is to identify the obstacles affecting deaf children and young people and how to overcome them. After much thought, we decided to choose an area that still continues to cause major problems. In the end, there was one obvious target: health.

We think that health is an extremely important part of a young person's life, but when we closely inspected it we found that it was flooded with challenges. Deaf young people were struggling to make appointments, understand the medical terms and words, and many more failed to know their rights in this area. Because of this, NDCS and the YAB both strongly feel that things need to change.

After deciding to explore the area of health, our aim was to investigate and reveal the main areas that needed to be fixed. Through an online survey and group discussions the following three key issues were revealed:

**Deaf awareness** - GPs and audiologists can be very useful, but only if you can understand them! This area mainly involves communication with deaf young people and how this can be improved.

**Access to information** – Do I understand what's going on in my appointment? Can I get an interpreter? How can you book by phone if you can't hear?

**Independence** - Growing up to be responsible for yourself is an extremely important part of life, but being deaf often puts a barrier in the way of this. We would like young people to feel more confident about visiting and booking appointments by themselves. On top of this, we aim to encourage children to get first hand information more often rather than it being relayed from a parent/guardian.

To establish evidence to support the campaign, the YAB set out to do the research themselves. This is because no one knows for sure what deaf children and young people want, except for them. This means the whole campaign is based on the actual opinions of deaf children and young people which we hope will help professionals and parents to make health services better. Overall, it makes the campaign extremely effective and confirms that all actions that will take place reflect the viewpoints of deaf young people themselves.

People often don't realise the seriousness of the issue so we've collected the information and squeezed it into a concise report. We really need people to take a few minutes to read this to raise awareness and to make explicit the importance of our message.



# Foreword from the President of the Royal College of Paediatrics and Child Health

A trip to the doctor or a hospital visit can be a nerve-wracking and confusing experience for any child or young person. Even more so, as this report reveals, when that child is deaf.

My Life, My Health uncovers the barriers that deaf young people face when accessing health services. They tell us clearly that they're not getting what they need from doctors. This isn't about medical treatment, but things that can be easily addressed such as difficulties accessing information and poor communication with healthcare professionals. There is no reason why, with the right support, deaf teenagers can't be as healthy, informed and independent as other young people.

The old adage 'if you get it right for children, you get it right for adults' is no more true than in case of deaf children. Effective management of young people's health will result in improved outcomes for them as adults. But too many deaf young people are at risk of poorer health outcomes as adults simply because they are deaf.

In recent years there has been a push to involve patients more fully in their care, giving them more voice, choice and control. Now this commitment has to be realised for the UK's 45,000 deaf children and young people.

As healthcare professionals, we have a responsibility to make sure every child and young person receives the highest quality care. This report and its recommendations provide a timely reminder that there is more to be done for deaf young people. By raising awareness of their needs and improving communication, we can give deaf teenagers the independence that they currently lack when it comes to their healthcare.

My Life, My Health marks the start of a campaign. The onus is on everyone – healthcare professionals, parents and deaf young people themselves – to turn this report and its recommendations into reality. If there's one message that's clear, it's that simple steps can, and will, make a real difference to the lives of these young people.



Dr Hilary Cass  
President, Royal College of Paediatrics and Child Health



# What we did and how we did it

YAB looked at issues affecting deaf young people

Picked health as their area for action

Drafted questions for and then launched online survey

Held 15 focus groups with deaf young people from all over the UK

Analysed the findings

Created this report and resources

**100**  
people aged  
11-18 years old  
did the survey

**117**  
took part  
in focus groups  
across the UK

The consultation findings contain the views of 217 deaf young people from across the UK, who shared their experiences via a survey and took part in focus groups.

100 deaf young people age 11-18 years old completed the survey.

In addition, 15 focus groups allowed more in depth discussions to take place and examples to be collected. 117 deaf children from across the UK took part in focus groups. Participants were aged 11-19 years, had different levels of deafness and communicated in different ways.

These focus groups were delivered by the NDCS Participation team and, where possible, co-delivered with YAB members who received training and were supported to facilitate the session. Focus groups were held in settings such as:

- mainstream schools with resource provisions for deaf children,
- deaf schools,
- youth groups for or attended by deaf young people.





# What deaf young people told us

## Deaf awareness

### Key findings:

- Deaf children and young people often come into contact with health professionals who are not deaf aware. As a result, they have to rely on family members to relay information during appointments.
- Many deaf young people depend on family members to book healthcare appointments on their behalf because booking systems are not accessible.
- Some deaf children and young people need help to know when their name is being called and said that using technology such as sign in screens and flashing LED visual alert systems was beneficial.
- Lack of deaf awareness and accessible systems mean that deaf young people are unable to be independent and are forced to rely on family members for support.

### Communication

The majority of deaf children and young people we spoke to told us that the people they met in healthcare settings lacked an understanding of deafness or did not know how to communicate with deaf people.

Many deaf young people rely on lipreading to support communication and need a good listening environment to get maximum benefit from their hearing technology or to utilise the hearing that they do have. However, these needs were often not supported in a healthcare setting with common experiences including:

- appointments taking place in rooms with background noise or poor acoustics,
- staff not looking at the deaf young person when speaking, meaning that they weren't able to lipread,
- difficulties in lipreading people with strong accents or beards,
- staff trying to have a conversation with the deaf young person when they have taken their hearing equipment off and not giving time for them to put it back on,
- staff talking to the parent and not including the deaf young person.

*“Some staff are clear and understandable but there are others that aren't because they either mumble or don't look at you when talking to you.”*

*“Sometimes they don't have any deaf awareness. It's really difficult to communicate. If you ask them to write things down they sort of huff about it and puff, but it's the only way to communicate.”*

*“It depends if they know if you're deaf or not; I think you have to indicate, so you have to tell them at reception and hope that they'll remember. But they do forget you've told them you're deaf.”*

Jasmine Jo, from London, made a video blog from her hospital bed, because she was feeling anxious about poor communication from hospital staff. *“I don’t understand what I’m being told. I’m being given injections but I don’t understand what’s happening,”* she said during the video.

In the video Jasmine is shown asking a doctor and a nurse about why she has been given medicine. A nurse hands Jasmine a piece of paper and a pen to write down what she wants to say, while another nurse appears to have some understanding of sign language as she correctly voices one part of the conversation but doesn’t utilise this skill further.

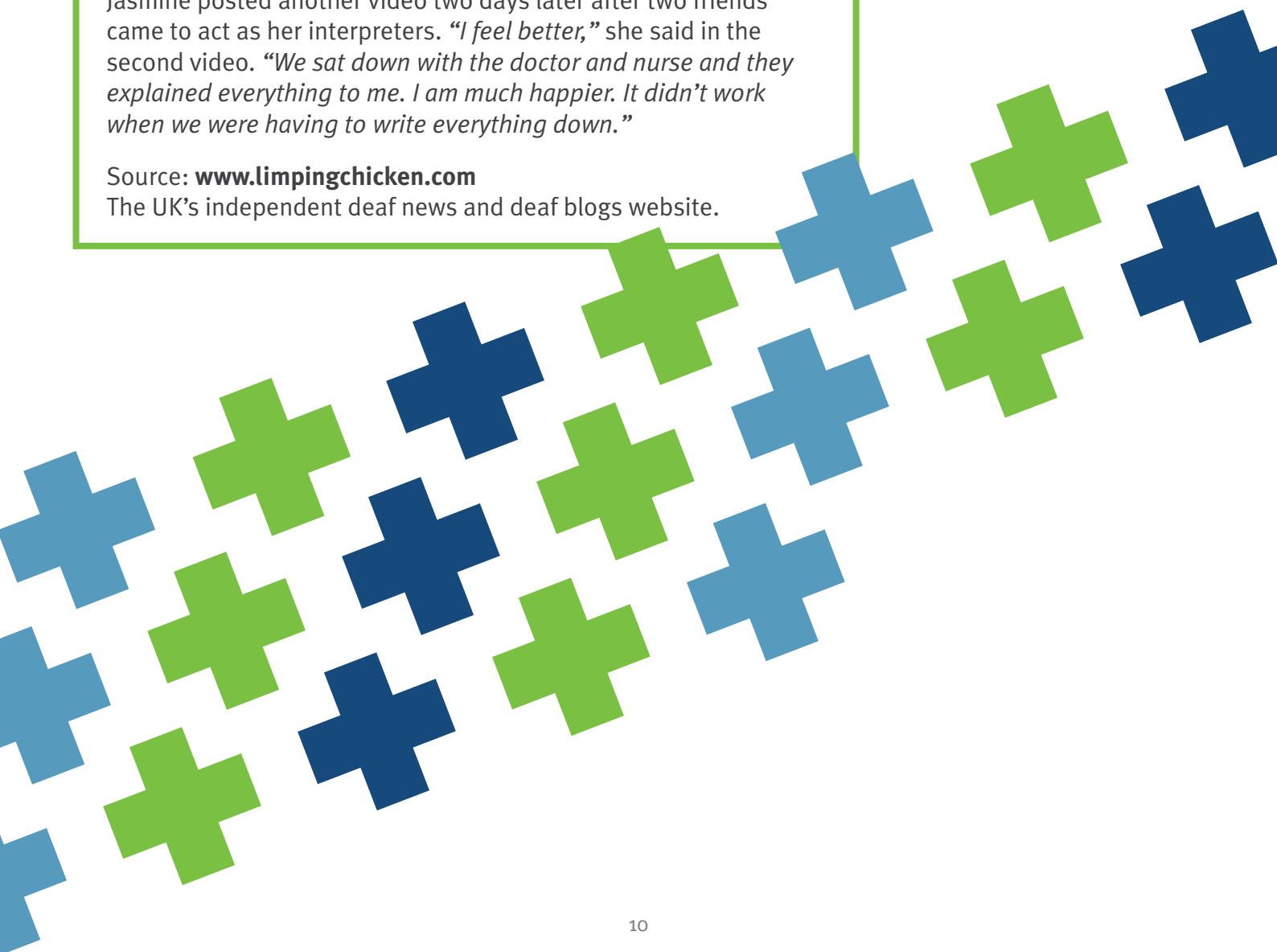
The first nurse tells Jasmine, while looking in another direction, that she will be moved. Jasmine doesn’t understand and doesn’t seem to know what the nurses are doing.

Once the bed begins to move, Jasmine appears panicked and signs: *“Where are we going?”* A nurse then writes down the destination with Jasmine repeatedly making the sign for *“I don’t understand”*. The nurse continues to speak to Jasmine with no effect. The video ends with Jasmine looking worried as she is pushed through a hospital corridor.

Jasmine posted another video two days later after two friends came to act as her interpreters. *“I feel better,”* she said in the second video. *“We sat down with the doctor and nurse and they explained everything to me. I am much happier. It didn’t work when we were having to write everything down.”*

Source: [www.limpingchicken.com](http://www.limpingchicken.com)

The UK’s independent deaf news and deaf blogs website.



## Alert systems and booking appointments

Deaf young people said they found it difficult when there were no visual alerting systems to let them know when it was time for their appointment. Some GP surgeries had sign in screens or visual alert systems that told people whose turn was next. Deaf young people welcomed this.

Where these weren't available, deaf young people worried that they wouldn't know when their name was being called. We were shocked to hear that one young person was being 'told off' for missing appointments when this was a result of her missing her name being called.

*"[Because of poor deaf awareness at my surgery] I've missed lots of appointments. I've just got one left and I've been warned not to miss another one."*

Incidents like this are not only discriminatory but cause unnecessary anxiety and distress to deaf children and young people, leaving them feeling particularly vulnerable.

Some deaf children and young people said that basic deaf awareness was a problem even before they entered the surgery or clinic and that a lack of deaf awareness also manifested itself in arrangements for booking appointments.

Deaf young people wanted to see surgeries and clinics use a wider range of technology so that appointments can be booked easily through online booking, text messages, email or Skype.

*"Doctors and audiologist should be using technology that we like to communicate with."*

*"When they were in the waiting room, if the name is being called out, you aren't going to hear that - should have a visual cue to indicate when it is your turn."*

*"I have to go to the doctors in person to book an appointment – where are my equal opportunities?"*

*"Not flexible booking methods – they told me to contact them by fax."*

*"Talk to me directly, speak loudly and clearly."*

## Deaf awareness – recommendations

- All health professionals should undergo basic deaf awareness training as part of their induction. Health professionals should also undergo refresher training when they come into contact with a deaf young person regularly. This must also be looked at in relation to ongoing professional development and training.
- Deaf awareness training should ensure health professionals are aware of the simple things they can do to improve communication such as ensuring eye contact, good lighting, avoiding speaking too quickly and learning a few basic signs.
- Medical records should make it clear that a child or young person is deaf and what their communication preferences are.
- All health settings should have visual alert systems or pagers so that deaf children and young people know when it is their turn.
- A range of systems should be in place to allow deaf children and young people to book their own appointments so that they don't have to make a telephone call or rely on family members. This should include email, online booking and/or text messages.

## Biomation – Top Tips for Health Professionals

In 2011, animation production company Biomation worked with deaf young people to create a film called *Top Tips for Health Professionals*. The film suggests ways to improve deaf awareness and communication skills amongst health professionals when working with deaf young people.

See [biomation.blogspot.co.uk/2011/06/top-tips-for-health-professionals.html](http://biomation.blogspot.co.uk/2011/06/top-tips-for-health-professionals.html)

# Accessible health information

## Key findings:

- Information being given to deaf young people by health professionals is often complex and hard to understand, with too much jargon. This leaves deaf young people feeling confused and alienated.
- Currently, many deaf children and young people are reliant on parents to provide communication support and tell them what's happening.
- There is a serious lack of understanding around the role of sign language interpreters and whose responsibility it is to arrange communication support. Some young people did not even realise communication support could be provided.
- Because communication support is not always provided by healthcare services, many deaf children and young people are reliant on parents to provide communication support and tell them what's happening.

## Using clear language

The use of complex language and medical jargon, when combined with communication barriers and lack of deaf awareness, can make for a frustrating and sometimes distressing experience for deaf children and young people. It is important that health professionals use language and examples that are children and young people centred. Asking questions can be a useful way to check a young person's understanding of what is being discussed.

*"Sometimes it is not easy to understand. For example, a doctor could be going into much detail using a lot of key words and facts that you don't know. Most of the time they don't explain them clearly."*

As a result of complicated language and jargon used by healthcare professionals, many deaf young people said that they have to ask their parents to attend appointments with them. Deaf young people may also try to get information from other sources. For example, 36% of deaf young people who responded to our survey said they accessed information for themselves online. This can sometimes be an issue if that information is not accessible or accurate.

Focus group participants said they wanted to see information presented in different ways to make it more appealing and accessible to deaf young people. This includes using visual clues, simple language and clean and clear design.

*"Some leaflets and posters are interesting because they are bold, bright and big. They are easy to understand!"*

*"I find that really difficult when I go to the doctor's. It goes way over my head. I need them to use simple words – clear, brief language, give examples."*

*"...when they talk to me it's way too complicated for me to understand!"*

## Communication support

Deaf young people's communication needs vary and it's important to ask them how they prefer to communicate and if they would like an interpreter. Some young people can communicate independently - providing the health professional is deaf aware and uses age appropriate language.

*"If it was personal, I'd rather not [have an interpreter]. I'd rather just make notes, have it written down... Sometimes the doctor understands me and sometimes not. If not, then we write things down."*

It is important where communication support is required for a deaf child or young person that a qualified interpreter is requested. Some deaf young people said they'd had experience of interpreters who were not skilled enough to provide adequate support.

Extra time will also need to be booked for the appointment so that the additional relay of information does not make the young person feel pressurised or rushed.

Other times, deaf young people turned up to appointments to find that no communication support had been booked.

We were shocked that some deaf young people - 13% of survey respondents and a large proportion in focus groups – didn't know they were entitled to any communication support. Others didn't know how to book communication support.

*"I don't think they [young people] realise they can do it for personal use, they think they would have to pay them and it is quite expensive. We need to tell them that they are entitled [to it]."*

*"My family and friends fed up coming with me to help for my communication support. I would prefer to have an interpreter to help me but I do not know how to book or get in contact with them."*

Some young people found that health professionals expected their family members to provide communication support.

*"I like professional interpreters there. If my family help, I feel like a little girl. No thank you."*

Some deaf young people said that having parents, friends or family providing communication support could mean that:

- information could be inaccurate,
- information could be missed,
- the support could become a burden,
- there could be awkward and embarrassing situations.

*"I'm scared that they don't tell me everything; my family don't tell me everything."*

*"It's all about me, it no-one else's treatment, why should I miss out?!"*

*"They often use communication support and sometime they wasn't in very good quality stage of signing. This is frustrating sometimes."*

*"The receptionist always forgets to sort my interpreter out because they are busy."*

*"What we want is to be treated as equals, so all the GP practices will provide interpreters."*

## Sign Health

We met a girl who used Sign Health's webcam remote communication support service ([www.signtranslate.com](http://www.signtranslate.com)) which enabled her to be independent (previously she always had to go with her parents). Sign Translate is an internet-based translation service that converts English to British Sign Language (BSL).

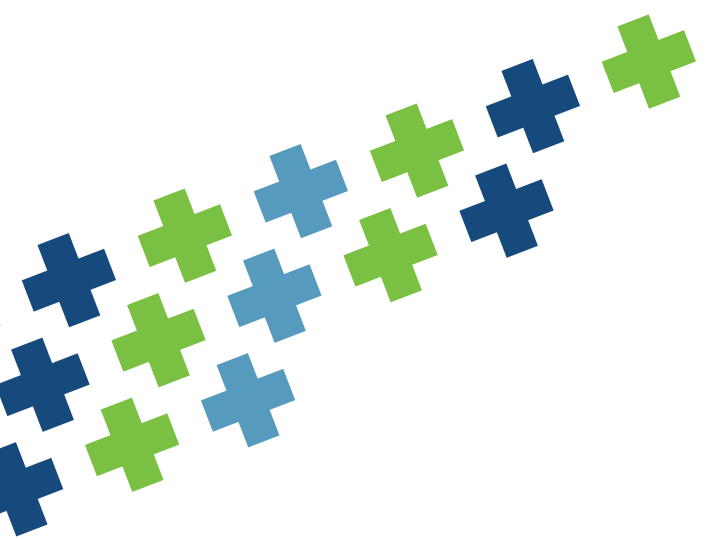
*There was communication breakdown. But it was better with the webcam and I could see somebody signing and communicating... an interpreter. And the doctor was there speaking and there was somebody there signing on the webcam. So, it wasn't a problem.*

## Accessible health information - recommendations

- Health professionals should ensure that information provided to deaf children and young people (both written and verbal) is clear, easy to understand and free of jargon. Health professionals must break information down into chunks so that deaf children and young people have time to take it in and understand it. They should check the young person's understanding throughout and leave extra time to go through any difficult concepts, explaining medical terms in written notes of advice. Information needs to be presented visually on leaflets and through the use of video clips.
- Having a confidential email contact that deaf young people can get in touch with if they are unsure about something.
- Deaf children and young people communicate in a range of different ways. Health professionals should ask what their communication preferences are and ensure this is recorded.
- It is the responsibility of health professionals to ensure that communication support is in place and booked before a deaf child or young person attends an appointment. It should never be assumed that family members will provide communication support.
- Deaf children and young people need to be provided with more information about communication support and the role of interpreters. They should be empowered to exercise their rights in this area, as well as their rights to good healthcare.

## Accessible communication

The Welsh Government and deaf organisations have worked together to create a set of standards for communication and information for people with sensory loss. These standards include many of the recommendations in this report and are used across the whole of the NHS in Wales. More information can be found here <http://wales.gov.uk/topics/health/publications/health/guidance/standards/?lang=en>.



# Becoming independent

## Key findings

- Most deaf young people lacked confidence about becoming more independent in managing their own health.
- The majority of deaf young people we spoke to were heavily supported by family, who booked and accompanied their children to appointments, and often acted as communicators.
- Young people want to see more done to promote independence. Many complained that health professionals rarely talked to deaf young people directly.

One of the key issues identified by the YAB, focus group participants and survey respondents was independence. As deaf young people become adults, they need to be empowered to take control of their own health.

Over 38% of deaf young people said they would not feel confident or very confident about explaining to staff that they are deaf.

*“I feel silly and annoying when I have to do it.”*

*“I find it embarrassing and like they’ll judge me.”*

*“Sometimes I do get bad reaction by people who didn’t know that I am deaf. And if people don’t know about deaf awareness, I feel awkward to explain to them, wronging them.”*

Nearly one in five deaf young people who responded to our survey said they would not ask their health professional to repeat information if they did not understand.

*“I am too scared and nervous”*

*“I’d just keep nodding and smiling :)”*

Other deaf young people felt more confident and some had created their own ‘deaf card’, explaining their communication support and needs.

*“I just state outright that I am deaf, so the staff are aware from the beginning.”*

*“I am confident because this is who I am. And I knew if I told them, we will help each other, working together.”*

The YAB were surprised to find that the majority of young people aged 15-16 were not even thinking about going to their appointments alone. Sometimes this was due to a fear that the health setting would not be deaf aware or that information would not be accessible. As set out earlier, improvements in these areas can give deaf young people more confidence to be independent.

*“I want to be independent. I am with my father because of no deaf awareness in my GP surgery.”*

*“I don’t go to audiology by myself yet. But in the future I may. I would find it difficult to answer questions. I would find it quite daunting although I have been going for years.”*

*“We need to be more independent in preparation for our future life, it is good for your confidence, you shouldn’t always go with you parents all the time.”*

*“They don’t have confidence because of the worry about communication breakdown. They rely on parents to give them access to information.”*

The YAB felt strongly that families and health professionals should be encouraging deaf young people in their journey to independence. Parents need to be careful not to be too overprotective.

Deaf young people who attended appointments with their families stressed the importance of being spoken to directly.

*“It makes me feel included, my doctors will always check out that I understand everything and that I have heard, they also let me voice my opinion!”*

A failure to speak directly to deaf young people encouraged them to be dependent on their families and left deaf young people with a range of negative feelings.

*“[I feel] stupid, because I’m there for myself not the parent, I’m the one with the hearing aids but they think they need to tell everything to the parent/guardian but the child has right to know is what happening.”*

*“They talk to my mum and I haven’t got my Cochlear Implant in. I’m still here!”*

*“It’s quite annoying if they tell my mum, then I’m like, well, why didn’t you tell me? It’s my problem, not my mum’s.”*

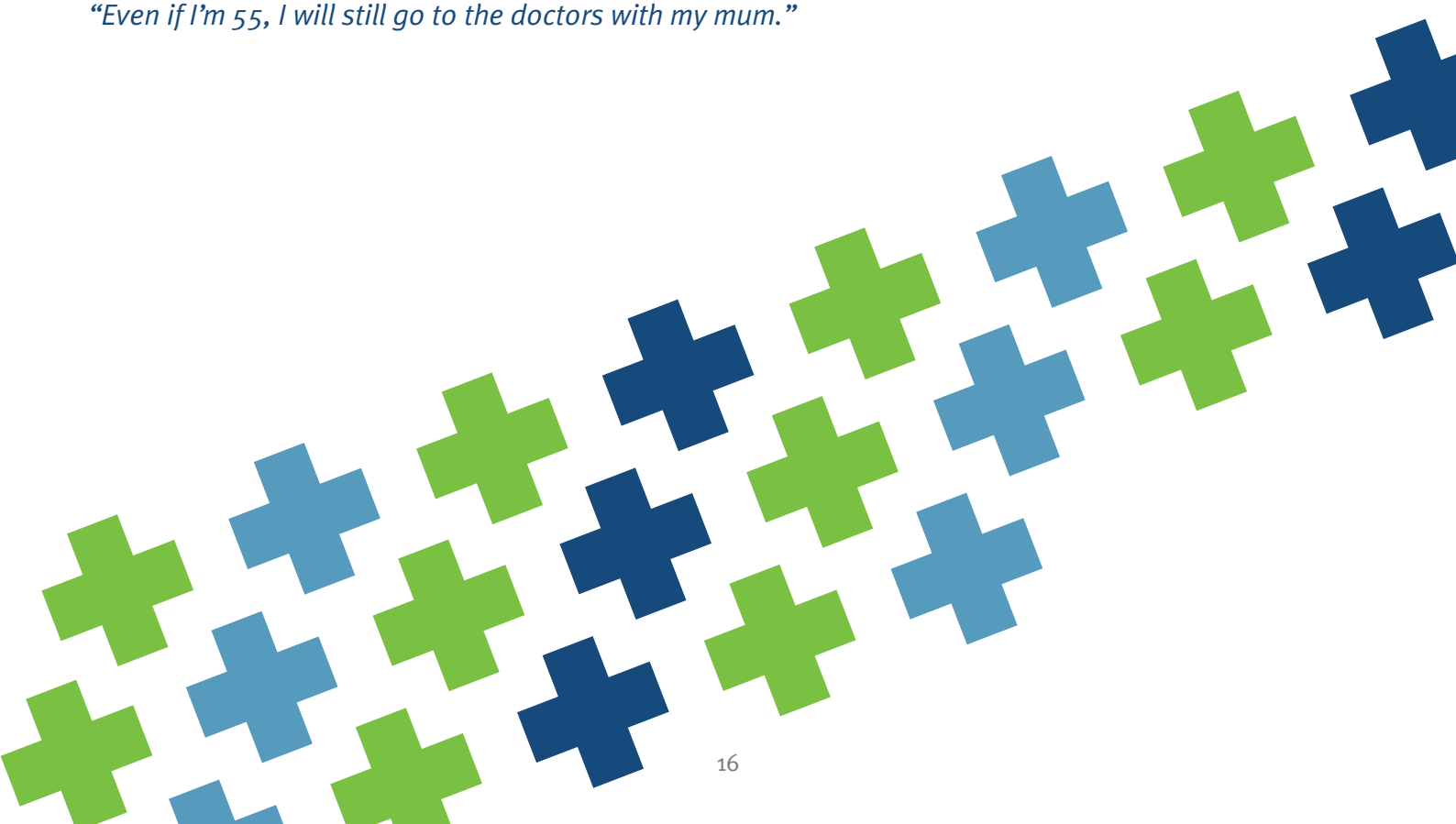
Deaf young people recognised that attending with family members was not always a bad thing. But it had to be done for the right reasons and in a way which didn’t promote dependency.

The YAB were particularly shocked that many deaf young people could not see independence at any point in the future. A number of young people mentioned that families supported them now, but in the future their girlfriend or boyfriend or children could support them. Some believed that parents would continue to support them, however old they might be.

*“Even if I’m 55, I will still go to the doctors with my mum.”*

*“They talk to my parents. Makes me very embarrassed because I’m 18.”*

*“So it is okay to ask somebody to go with you for support; it is not okay to have to take somebody with you because they have to do your talking for you, that’s wrong.”*





## Becoming independent – recommendations

- Ensuring basic deaf awareness is in place and that information given is accessible are both vital preconditions to independence.
- Deaf young people must be empowered, supported and encouraged to clarify, ask questions and make sure they understand. They should be provided with information about the importance of becoming independent in their health care and be clear on the steps they can take themselves to progress this.
- As deaf young people get older and more confident, health professionals must always talk to deaf young people directly, and not to their parents or interpreters.
- Deaf children and young people and their families need support to work out when and how they will begin their journey to independence. Health professionals and parents have a role to play in ensuring and encouraging deaf young people to take these steps to independence.
- Transition to adult services must be carried out in consultation with the young person and their family to ensure that deaf young people are ready and confident about the move.

## Audiologist's view

*“As they start getting older, I discuss with the parents about independence in appointments. I start to talk to the parents in the waiting room and ask are you going to wait here? Shall I take him in on his own? And do it gradually, so the parents are there if needed to support. They can email me to ask for an appointment so they don't need mum to ring and make it for them. Eventually they start coming on their own and we do it gradually like that.”*

## Supporting transitions

*“We went to a transitions clinic in Wolverhampton where deaf young people come along to find out more about adults services, technology, local services and national opportunities - I have not seen that elsewhere. It is useful for parents if they are thinking about equipment or information about accessible services, and I think that should be modelled elsewhere really.”*

For more information, take a look at NDCS's *Transition Quality Standards* found here [www.ndcs.org.uk/professional\\_support/transition](http://www.ndcs.org.uk/professional_support/transition)

# Conclusion

This report has shown that deaf children and young people face a range of barriers in accessing healthcare services. Deaf children and young people are missing out on vital information about their own health and being forced to rely and depend on family members when they should be moving towards independence. This can only have negative consequences for their future health and well-being. It can also result in greater costs for the NHS if deaf young people grow up without an understanding of what they can do themselves to promote good health.

In this report, we set out some of the simple steps that can be taken to improve deaf young people's access to health services. Deaf children and young people themselves should be at the heart of these changes. Ensuring their meaningful participation at all levels will ensure they benefit from these changes and that we meet the goal of child-centred care.

NDCS wants to support health professionals in these changes and have produced a range of resources to promote better deaf awareness, accessible information and greater independence for deaf young people. These are available online at [www.ndcs.org.uk/mylifemyhealth](http://www.ndcs.org.uk/mylifemyhealth). We hope deaf young people, parents and health professionals read our report and use our resources to make sure deaf young people get the most out of their health care.

To find our range of resources go to [www.ndcs.org.uk/mylifemyhealth](http://www.ndcs.org.uk/mylifemyhealth).



# About NDCS

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

NDCS helps deaf children and young people and their families by providing practical information and support.

The Young People's Advisory Board (NDCS YAB or YAB) exists to advise NDCS on issues that affect deaf children and young people aged 8–18 across the UK.

The YAB ensures deaf children and young people have a voice in all matters that affect their lives both at a local and national level. The Board is made up of 17 deaf young people 12–18 years from all over the UK. The young people have different levels of deafness and use varying communication approaches.

## Thank you

We would like to say a special thank you to each of the 217 deaf children and young people who participated in consultation activities and the online survey, and shared their experiences, views, ideas and aspirations for their health services. Thank you to those that supported the planning and accommodation of the visits - this report would not have been possible without you.



# Has this report inspired you to change things?

NDCS have produced a range of FREE materials to improve access to healthcare for deaf young people.

## For healthcare professionals

### Supporting deaf teenagers during their appointments

This leaflet contains deaf awareness top tips for professionals and suggestions of how to support a deaf young person become more independent.



## For parents and carers

### Supporting your deaf teenager to manage healthcare appointments

This booklet identifies common worries that parents and carers may have and suggests solutions which will improve a teenager's independence.

## For deaf young people

### 'Hello I'm deaf' wallet card

This card can be personalised to help explain what the deaf young person requires from others to communicate in the best way. Designed to be kept in a young person's wallet, it can be used in many situations to help others understand about a deaf young person's needs.

Hello,  
I'm deaf

ndcs  
every deaf child

## I need...

- an interpreter
- you to face me
- you to speak clearly
- you not to shout or mumble
- you to not talk & type at the same time
- to see your mouth so I can lipread
- a quiet space/no background noise
- us to write stuff down
- us to be patient and not give up

Don't worry,  
it's easy

## For deaf young people

### 'Are you ready to go to the doctor by yourself?' quiz sheet

This easy to follow quiz helps young people think about if they are ready to go to the doctors alone and gives suggestions of how to build confidence and improve access.

## Are you ready to go to the doctor by yourself?!

Do this quiz to find out.

### 1 You need a doctor's appointment. What do you do?

- No idea - my mum, dad or my carer always book them for me.
- I book my appointment myself.
- My mum or dad book them for me - I tell them which date and time are OK for me.

### 2 Eek! You've got an embarrassing problem 'down there'. What do you do?

- I will tell my parents and they will come with me to the doctor.
- I don't have to involve my mum or dad because I can book an appointment with my doctor myself.
- No way I'm telling my parents about it! I'll ignore it and hope it goes away.

### 3 You want to use sign language during your appointment. What do you do?

- I'll ask the doctor's surgery to arrange an interpreter for my appointment or we'll agree to use a video translation service.
- I'm not sure how to book an interpreter so I'll just struggle through it without one.
- I'll take a member of my family or a friend to interpret for me.

### 4 Ok, so you've arrived for your appointment. Do you speak to the receptionist yourself?

- Yes - I tell the receptionist my name and the time of my appointment.
- Yes - I sign in myself and remind the receptionist to come and get me when it's my appointment.
- No, whoever I'm with does it for me.

### 5 You've been in the waiting room for ages, but no one has come to see you. You are worried you have missed your appointment. What do you do?

- I don't do anything - mum sorts it all out.
- I'd feel embarrassed to ask the receptionist if I had missed my turn.
- I'd go to the receptionist to find out what's going on. I'd check they have remembered to come and get me when it's my turn.

### 6 Your doctor turns away when they are talking to you. What do you do?

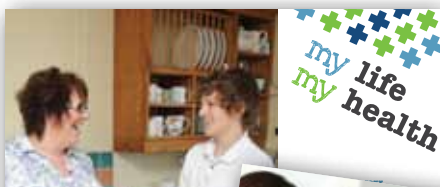
- I get too embarrassed to ask what they'd said, so I'd just nod and smile.
- I'd remind them to face me when they talk to me and ask them to repeat what they said.
- I'd apologise and ask them to repeat it.

### 7 There's a question you really want to ask during your appointment. What do you do?

- I'd probably be OK to ask the question and then hope I understand the answer.
- I'd feel too nervous to speak. I'd just let mum or dad do all the talking.
- I'd ask the question then make sure the doctor explains their answer so that I understand. If I don't understand I'd ask them to explain it again.

#mylifemyhealth

Now add them up!  
Which colour came up the most?



my life  
my health



my life  
my health

### Ready to go to the doctor by yourself?

Feel ready to start going to the doctor on your own? Talk to your parents and find out how they can support you!

### Communicating when I visit my doctor

Sometimes going to the doctor can be difficult, right? Especially if you have a hearing aid, it's hard to communicate with your doctor. Here are some tips to help you.

"I find that really difficult when I go to the doctor's. It goes way over my head. I need them to use simple words - clear, brief language, give examples."

**Use BSL?**  
Interpreters are here to support you during your appointment. Check out this video to find out what it's like to have an interpreter in your doctor's appointment.  
[buzz.org.uk/mylifemyhealth](http://buzz.org.uk/mylifemyhealth)

**The law**  
The law says that all health services - like your doctor's surgery or hospital - have to ask what extra things they can do so that deaf people like you can get the health services you need.

**Want more information?**  
Signhealth  
Useful information about healthcare for BSL users.  
Check out our videos for BSL users on the Buzz: [buzz.org.uk/mylifemyhealth](http://buzz.org.uk/mylifemyhealth)

**Can't use the phone to book?**  
Tell your doctor's surgery the things they can do to make booking an appointment easier for you. For example, by giving you the option to book by text, online or by email.

It should be easy to get help from your doctor's surgery, no matter what support you need. This includes making sure that your deafness doesn't get in the way of booking appointments.

**Your rights**  
You have a right to be involved in discussions and decisions about your health and care. You should be given information to help you make decisions.

**Unhappy with your doctor?**  
If you're not happy with your doctor, you can ask for a second opinion or a different doctor.

## For deaf young people

### Information sheets

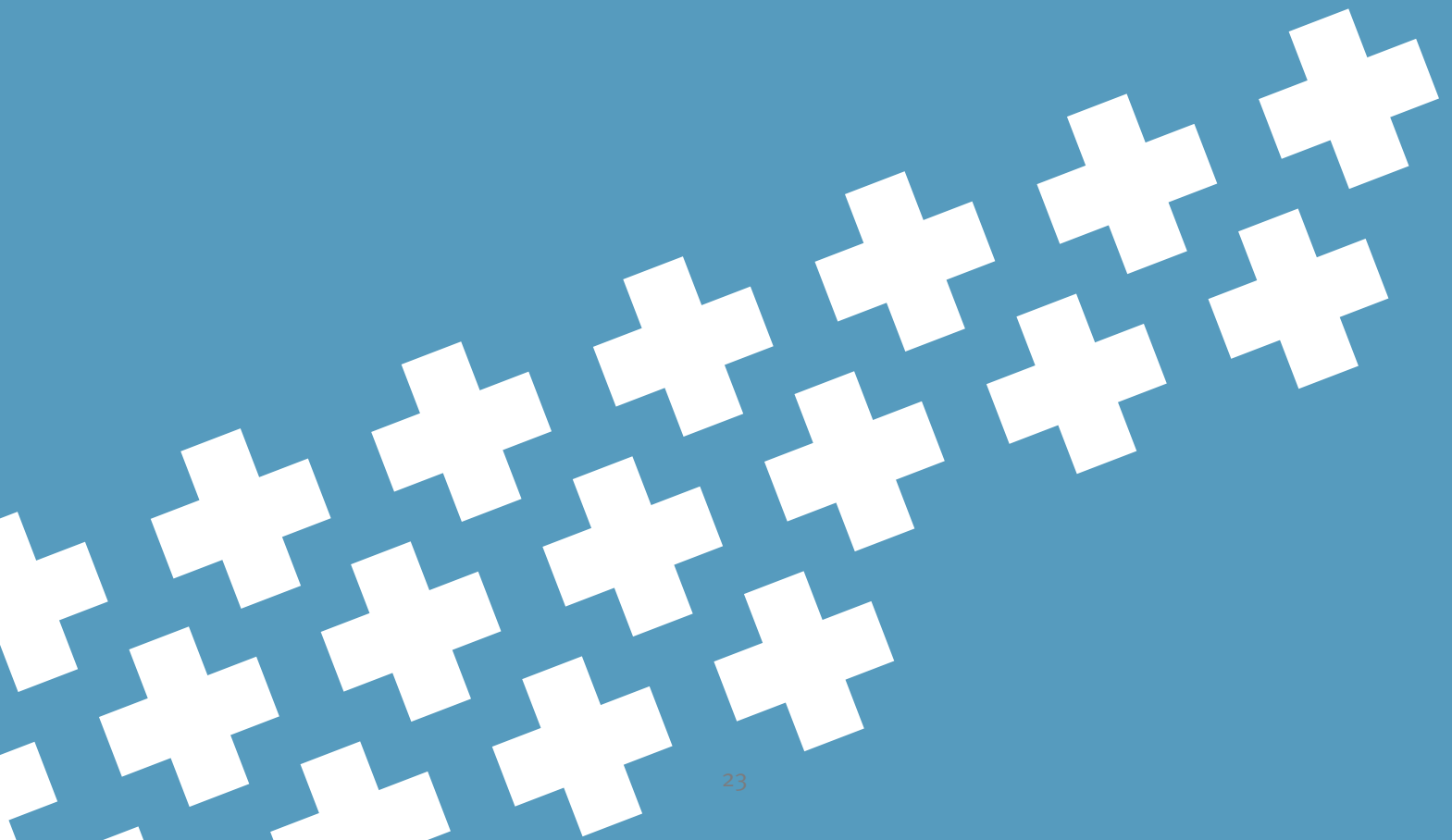
A selection of information sheets which cover all stages of going to the doctors. There is also a health words glossary and lots of British Sign Language (BSL) resources online.

To find our range of resources go to [www.ndcs.org.uk/mylifemyhealth](http://www.ndcs.org.uk/mylifemyhealth).

# Notes and ideas

A series of horizontal dotted lines for writing notes and ideas.

“Even if I’m 55  
I will still go to  
the doctors  
with my mum.”



**NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.**

**NDCS Freephone Helpline:  
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**helpline@ndcs.org.uk**

**www.ndcs.org.uk**

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**ndcs**  
  
**every deaf child**