

A woman with short brown hair, wearing a white lab coat over a yellow top and dark trousers, is seated in a black wheelchair. She is looking towards the camera with a neutral expression. The background shows a laboratory or clinical setting with a microscope on a table to the left and a window with blinds behind her. The overall lighting is soft and natural.

**ALONE WE  
CAN DO SO LITTLE;  
TOGETHER WE  
CAN DO SO MUCH.**

Helen Keller

**Brochure for healthcare workers  
on dealing with persons with  
disabilities**

WITH FUNDING FROM  
 **AUSTRIAN  
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EMPOWERS PEOPLE WITH DISABILITIES

In this photo:  
Dr Belma Goralija  
Clinical cytology specialist

**ALONE WE  
CAN DO SO LITTLE;  
TOGETHER WE  
CAN DO SO MUCH**



### **Helen Keller**

*American author and activist*

1880-1968

Helen Keller was an American author and political activist. She lost her eyesight and hearing in early childhood, but nonetheless learned to communicate, thanks to her exceptional perseverance and determination.

The first deaf and blind person to graduate from university, she was an active campaigner on both political and social issues, fighting for social justice and the rights not just of persons with disabilities, but of women and workers generally.

Because of her achievements in the fields of literature, education and social activism, she received honorary doctorates from universities around the globe. She met with every serving American president over the course of her life and greatly impressed such famous individuals as Alexander Graham Bell and Mark Twain.

Hellen Keller became one of the most famous deaf-blind people in the world and contributed to the shattering of stereotypes about persons with disabilities by proving through the example of her own life how they can fulfil their full potential.

# **Brochure for healthcare workers on dealing with persons with disabilities**





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## Impressum

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*All expressions using the male form of the grammatical pronoun in this document should be understood as referring, without distinction, to both men and women.*

## **Who is this brochure for?**

Potential readers include healthcare professionals of various backgrounds: consultants and doctors in training across all specialisations, nurses, medical technicians, psychologists, social workers, and anyone else working in or with healthcare institutions and facilities who may have contact with patients. We hope it will help improve how patients with disabilities are dealt with. The brochure will also be distributed at medical high schools and faculties to introduce students to basic aspects of how to deal with individuals with disabilities and how to work on and develop their “bedside manner”. As it deals in detail with how to meet the needs of persons with disabilities, particularly physical access to facilities and ensuring communication and information are available in appropriate forms, the brochure may also be of use to healthcare managers involved in developing policy and strategies and in planning the allocation of budgetary resources for such purposes.

## **What is this brochure for?**

This brochure is intended to help healthcare staff learn and develop their skills and so improve how they deal and communicate with persons with disabilities, regardless of gender or age. We hope this will result in better assessment and a higher quality of healthcare provision. Discriminatory behaviour is often due to a lack of information on the rights of persons with disabilities and how best to meet their needs.

This brochure contains information that can help healthcare staff adjust how they approach and deal with individuals with disabilities, increasing everyone’s satisfaction. At a broader level, we expect the brochure to contribute to raising public awareness of disability issues.

## **What is in this brochure and what is not?**

Much of the brochure is “first aid” for healthcare staff and should help them understand the difficulties patients who happen to have a disability face and so deal with them more appropriately, contributing to the quality of their patients’ lives and increasing their own job satisfaction. Disability is a highly complex and heterogenous phenomenon, even without taking personal characteristics, like age, gender, and social status into account. The authors of this brochure make no claim to have dealt with all the requirements or characteristics of all forms of disability.

We point out in the text that much of the advice on individuals who are blind or deaf or have some other forms of physical disability applies equally to children with those disabilities. Similarly, while a section of the brochure has been dedicated to children and young people with disabilities, given the growing number of developmental and behavioural disorders, most of the advice given there in relation to young people of up to 30 years of age naturally also applies to older people with the same disability.

The publication contains several general recommendations on communication, as a fundamental precondition for success in relating with patients. It is our hope this may help healthcare workers in establishing and maintaining satisfactory relations with patients with disabilities. The brochure also discusses certain practices aimed at making healthcare services and procedures more accessible to persons with disabilities. The discussion of the accessibility of facilities is intended to acquaint healthcare experts with the steps required to make them accessible *to persons with disabilities*.

## How to use the brochure

For the purposes of this brochure, to help the reader in understanding specific aspects of accessibility and communication for persons with different types of disability and to assist him in finding the content he needs most at any given time, we have divided up the contents as follows:

- Communication with, the accessibility of healthcare services, procedures, and facilities to, and the accessibility of information to children and young people with disabilities;
- Communication with, the accessibility of healthcare services, procedures, and facilities to, and the accessibility of information to people who are deaf or hard of hearing;
- Communication with, the accessibility of healthcare services, procedures, and facilities to, and the accessibility of

information to people who are blind and have impaired vision;

- Communication with, the accessibility of healthcare services, procedures, and facilities to, and the accessibility of information to persons with physical disabilities, and
- Communication with, the accessibility of healthcare services, procedures, and facilities to, and the accessibility of information to persons with mental disabilities.

All the specific and general recommendations made regarding communication with children, young people, and adults with disabilities should be viewed in terms of the needs of the individual. They should be integrated into a holistic approach. For example, while recommendations for communicating with adults who happen to be deaf or blind are also relevant to communication with children who are deaf or hard of hearing or blind or have impaired vision, the principle of difference and the richness of each person's individual identity, quite independent of their disability, must always be kept in view.

## Acknowledgements

The MyRight organisation has coordinated preparation of this brochure and would like to thank everyone who participated for their goodwill and interest and time spent writing, commenting on, revising and generally contributing to the publication.

## Preamble

The Agency for Quality Assurance and Accreditation in Healthcare in the Federation of Bosnia and Herzegovina (AKAZ) and the Agency for Certification, Accreditation, and Improving the Quality of Healthcare of the Republika Srpska (ASKVA) have been working closely with MyRight – Empowers people with disabilities since 2014 on our common goal of ensuring a health care system that is more inclusive of persons with disabilities.

My Right has working with an established network of organisations of persons with disabilities to develop its programme for strengthening the knowledge and skills of persons with disabilities and their organisations. One result is that their needs and rights have been successfully incorporated into the accreditation and certification standards applied by mental health centres in both entities of Bosnia and Herzegovina (the RS and the FBiH) and by family medicine teams in the FBiH. Indeed, both the abovementioned agencies have been working on their revision over the past year. We therefore fully recognise the need for and value of building better relations between healthcare professionals, as the service providers, and persons with disabilities, as the users of their services, with their own specific requirements.

I consider the decision taken by the disability community, with the support of our agency, to draft this brochure, not just a good, but an exceptionally useful one. I am convinced it will be of great assistance to everyone working in healthcare in their efforts to respond to the challenges they meet in their work and particularly in dealing with patients who happen to have disabilities. As a representative of an agency whose basic goal is the continuous improvement of quality and safety in healthcare institutions and healthcare more generally, I have the greatest respect for the expertise brought to the process by the individuals with disabilities involved in drafting this brochure.

The brochure will certainly make our work easier and improve the understanding healthcare workers have of the rights and needs of persons with disabilities, particularly regarding better communication, better access, and better ways of approaching this sizeable section of our society. The brochure is also certain to be useful for society as it meets several Bosnia and Herzegovina's international obligations, specifically those related to respect for the human rights of persons with disabilities and patient rights. It is my honest hope and recommendation to serving and future healthcare professionals that they study and make use of this brochure. I am convinced that application in practice of the recommendations set out in it will result in higher levels of satisfaction for both healthcare professionals and for our patients.

*Dr Ahmed Novo, Director of AKAZ*

## Few words by peer reviewer

At last we have a Brochure for healthcare staff on dealing with persons with disabilities written by the people most affected. It offers an opportunity for all of us to learn fundamental principles that will assist us in establishing more relaxed communication with our patients with disabilities, so that everybody involved is more at ease in such interactions. There is a wealth of evidence from academic studies and day-to-day experience that communication between healthcare staff and patients is beset by a range of problems. These problems are only exacerbated when the patients involved are individuals with disabilities.

Healthcare staff must accept the fact that their patients can often be their best teachers, particularly when it comes to the burdens, temptations, and wants that sickness or a disability can bring with it. Communication is one area in which we have much to learn from our patients. It is only logical that they should be the ones to tell us what they want and expect, what bothers them, and how we should address them. This brochure offers those of us working in healthcare answers to these questions.

The authors state that “... All individuals with disabilities consider themselves equal and independent...”, but that is only part of the truth. In my view, individuals with disabilities are not just equal partners, but experts on their own problems. That is why we must accept their suggestions, advice, and ideas. Marta Funnell was surely correct when she wrote, in an article “Helping patients take responsibility for their own chronic illness”, that patients are the experts on their own lives. Doctors and nurses no doubt know more about illnesses like diabetes, kidney failure, or heart attacks, but the ones who know most and best about how such conditions and ailments affect their everyday life are the people who live those lives. We must be open with and learn from our patients.

In reading this brochure, I was reminded of one of my own teachers and mentors. Let me call him Halim. He taught me many things in both my personal and professional life. At the beginning of my professional career, I was searching for the best way to communicate with patients. I felt strongly my lack of knowledge and skill in this area. I found it personally uncomfortable talking with the very sick or dying or people with disabilities. I often made mistakes, something I found rather difficult to cope with. Then, one day, Halim turned up in my waiting room, with his dark glasses and white cane. Not long into our conversation, he asked: “Doctor, why are you shouting? I can’t see, I’m not deaf!” That is how my training began over the next couple of years. As Halim’s illness developed, I would visit him with increasing frequency in his own home, along with my colleagues, the senior medical

technician Tomislav Krmpotić, and the registered nurse, Ad-  
vija Čustović. On one occasion, I turned to his wife to discuss  
Halim's diet and he admonished me: "Doctor, please address  
me, not her. After all, I'm the patient, here."

I remember those conversations well. Even now, I remain  
charmed by his life force, his positive attitude, and his sense  
of humour, generally at his own expense, and all despite the  
hard life he had had and the diseases that had afflicted and  
limited him. I miss his smiling face and the sentence with  
which he would inevitably greet me: "Doctor, haven't seen  
you in ages!"

He taught me an important principle of learning - learn from  
those who know best. This brochure is a chance for all of us  
working in healthcare to learn from the teachers who know  
best what we need to learn.

*Dr Zaim Jatić, Associate Professor at the Faculty of Medicine*

# GLOSSARY

**Braille** - relief form of script for the blind, involving combinations of six indentations in special paper which represent letters and numbers.

**Disability** - the concept of disability is a developing one. Disability arises out of the interaction between an individual with impairments and barriers in their environment or reflected in social opinion, which hinder their full and effective participation in society on an equal basis with the other members of society.

**Person with a disability** - a person with a long-term physical, mental, intellectual or sensory impairment which, in combination with various barriers, can hinder full and effective social inclusion on an equal basis with other members of society.

**Orthopaedic or other aids/assistive devices** - aids and assistive devices to help persons with disabilities achieve equality of opportunity in participation in all aspects of life and society.

**Orthopaedic aids/assistive devices** - aids or assistive devices tailored for individuals with physical disabilities, including mechanical or motorised wheelchairs, canes, walking frames, prosthetics, orthopaedic shoes, etc....

**Reasonable accommodation** - necessary and appropriate modification or adaptation that does not represent a disproportionate or unacceptable burden and is required in specific cases to guarantee that individuals with disabilities can enjoy and exercise their human rights and fundamental freedoms on an equal basis.

**Hearing aids and assistive devices** - aids designed for individuals who are deaf or hard of hearing individuals, including analogue and digital hearing aids, inserts and implants, light alarms for crying children, light or vibrating alarms, etc....

**Assistive devices and technology for the visually impaired** - aids designed for the individuals who are blind or visually impaired, including canes, watches and alarm clocks, speaking thermometres, sound recorders and players, Braille writing devices, and note recording devices for the blind persons, etc....

**Universal design** - an approach to designing products, environments, programmes and services that allows everyone to make the best use of them without additional adaptation. Universal design does not exclude the existence of assistive media or devices for persons with disabilities, when such devices are necessary.

**Healthcare workers and professionals** - people with secondary or tertiary education in disciplines related to healthcare and medicine and who are directly employed in providing healthcare to the public, with mandatory respect for the moral and ethical principles of the healthcare professions. This includes doctors working as consultants or still in training in all the different specialisations, nursing staff, medical technicians, psychologists, dentists....

**Sign language** - a natural human language based on visual cues and hand gestures used by the deaf and hard of hearing communities.

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## Introduction

The population with disabilities is a varied group united by certain forms of functional damage to hearing, sight, mobility, communication, learning/cognitive processes, or psychosocial and other conditions that significantly limit one or more major aspect of their life and activity. Disabilities may be obvious and visible or not immediately visible (e.g. MS, diabetes, deafness, mental difficulties, and other ailments or conditions). Members of this population are to be found in any age group, from earliest childhood to our final years, and in both genders. Individuals with disabilities are a sizable proportion of the population. Indeed, according to the World Health Organisation<sup>1</sup>, they make up as much as 15% of the world's population. As the population ages and the prevalence of chronic, autoimmune, genetic, and rare diseases increases, along with the tempo and manner of modern life, we all face the prospect of disability at some point in our lives. It is in our own interest, if nothing else, to engage and join the fight to ensure we have access to what we will surely need,

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<sup>1</sup> <http://www.who.int/mediacentre/factsheets/fs352n/>

when, sooner or later, we face that eventuality. This brochure is intended to encourage healthcare providers to do their best to integrate the population with disabilities in all areas of public healthcare, from prevention to early intervention to tertiary healthcare.

This brochure for healthcare staff on dealing with people with disabilities is a product of the project for *The effective inclusion of people with disabilities in healthcare in Bosnia and Herzegovina*. This project is part of a capacity-building programme for persons with disabilities being implemented in Bosnia and Herzegovina by MyRight-Empowers people with disabilities and financed by Light for the World and the Austrian Development Agency (ADA).

Representatives of five coalitions of organisations of persons with disabilities from Bijeljina, Dobož, Tuzla, Sarajevo, and Mostar participated in the drafting of this brochure, as did parents and experts from organisations that are not members of those five coalitions, but were kind enough to contribute their considerable experience and knowledge to the process of developing the brochure, ensuring its quality. Healthcare professionals also participated in drafting the brochure, providing an additional dimension from the perspective of its intended users.

We hope that healthcare staff and service providers will welcome this publication, as the first of its kind to be produced in Bosnia and Herzegovina, and that it will prove useful to them

in their work. We also hope that the brochure helps inspire better and more ambitious projects to improve the treatment of persons with disabilities even further.



# 1.

## **The United Nations Convention on the Rights of Persons with Disabilities**

Bosnia and Herzegovina ratified the United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol in March 2010, without reservation or comment.<sup>2</sup> Regardless of the state's complex structure and organisation, division of jurisdictions, or how particular issues are dealt with differently in law and regulation at the various levels of government, by signing and ratifying the international conventions on human rights, Bosnia and Herzegovina accepted an obligation towards its own citizens throughout the state, without discrimination on any basis, to guarantee them equality of conditions.

<sup>2</sup> [http://tbinternet.ohchr.org/\\_layouts/TreatyBodyExternal/Treaty.aspx?CountryID=22&Lang=EN](http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Treaty.aspx?CountryID=22&Lang=EN)

Bosnia and Herzegovina has an obligation to meet human rights standards arising from international documents the country has signed and ratified. All people with disabilities have the right to protection from discrimination and to full enjoyment of all their human rights, as set out in and guaranteed by these international instruments.

Even before ratification of the UN Convention, all members of society had a guaranteed right to health under the Universal Declaration of Human Rights, which is referenced in the preamble to the Constitution of Bosnia and Herzegovina.<sup>3</sup>

Individuals with disabilities have the same rights to access to healthcare services as every other member of society. This is clearly stated in articles 23, 25, and 26 of the Convention on the Rights of Persons with Disabilities. The fact that a person has a disability does not per se preclude a satisfactory level of health. Many people with disabilities lead healthy, active and fulfilling lives, including work and an active social life, sporting and other leisure activities, a healthy sexual life, and parenthood. Unfortunately, many people with disabilities do suffer from poor health and quality of life, in comparison to their peers without disabilities.

The obligations assumed by the state and the entities by ratifying the UN Convention entail a requirement to allocate budget resources for the necessary reasonable accommodation of premises, to ensure accessibility, for the provision of assistive technologies, for employee training, and to facilitate

communication, including the provision of sign language interpreters, materials in Braille, tactile communication, large font documents, accessible multimedia content, the use of text (in addition to oral instructions and explanations), audio recordings, et cetera.



## 2.

### **Accessibility as a basic precondition for enjoying fundamental human rights**

The concept of accessibility encapsulates everything required to ensure equality of opportunities, as well as full and equal access to the enjoyment of all human rights.

Reducing barriers to access does not generally require major resources, but goodwill, an acceptance of the need for alternative forms of access, and reasonable accommodation regarding how information is presented, communication conducted, and services, procedures and facilities made accessible. Reasonable accommodation means adaptations that do not require excessive effort or additional resources

compared to the benefits they bring, particularly for better relations between staff and service users with disabilities. MyRight carried out monitoring of respect for the human rights of persons with disabilities during 2012 and 2013 in five regions in Bosnia and Herzegovina, using the demanding DRPI (Disability Rights Promotion International) methodology.<sup>4</sup> This was done in cooperation with our five partner coalitions of organisations of persons with disabilities, active in the Bijeljina, Dobo, Tuzla, Mostar and Sarajevo areas. In-depth interviews were carried out with a sample of 100 individuals with different forms of disability. This meant conducting free-ranging and relaxed conversations with the said individuals, in a natural environment, about their firsthand experiences over the preceding five years. Use of the DRPI methodology means the interviewers also have disabilities. The interviewees shared firsthand experiences, including these of using healthcare services, a significant life issue for most individuals with disabilities.

In most cases, the interviewees complained that communication with healthcare staff was more difficult than it needed to be. These difficulties were sometimes caused by failures to understand the language being used, whether by medical staff or by the individuals with disabilities, but also by a lack of the patience or time required to communicate successfully with individuals with certain forms of disability. Another potential cause of poor communication is lack of familiarity with the individual patient, who happens to have a disability. Moreover, training programmes at medical high schools and

faculties, dentistry faculties, and healthcare studies faculties do not provide sufficient theoretical or practical training about the characteristics and needs of individuals with different forms of disability. Finally, most medical staff simply don't have enough practical experience treating individuals with disabilities, which results in a lack of sensitivity towards them.

The continued presence of physical barriers preventing access to health care facilities or the equipment for providing services is a major problem. It often means services are inaccessible to patients with disabilities and not infrequently results in situations that represent an affront to their personal dignity or even physical injury. Annex 1 to the brochure presents some of the more important results of monitoring carried out in healthcare institutions and facilities in Bosnia and Herzegovina, particularly of their accessibility or lack of it. Nonetheless, physical barriers and poor accessibility to services and information are only some of the reasons individuals with disabilities do not always go to the doctor when they need to. This puts their health at risk and increases the final cost of health care.

What accessibility of facilities and services and access to information mean for persons with disabilities is something you can get a taste of through a simple experiment. Try putting a bandage over your eyes and sitting in a wheelchair. Then, set off to visit a healthcare facility. Or just turn the sound down on the television and try to follow the programme. Just how long would an individual without impaired hearing keep fol-

lowing a television programme like the news with the sound turned fully down, before they began to get angry or nervous? Or, try to imagine the fear and discomfort involved in being carried in a wheelchair upstairs by people you don't know and who aren't particularly strong and have little experience doing such things. And then think about how few multi-storey healthcare facilities in Bosnia and Herzegovina have a lift.<sup>5</sup> Once you have succeeded in getting into the appropriate section of the healthcare facility, there is the effort required to overcome quite unnecessary physical barriers, like a pointless raised threshold between the waiting room and the examination suite. Not to mention the problem of toilets for patient use, as very few healthcare institutions have bathrooms adapted for use by wheelchair users.<sup>6</sup> There are so many potential dangers there to test individuals with disabilities, like slippery floors, damaged flooring, boxes or containers placed on the wall at shoulder height or bins and ashtrays placed immediately beside doors. Just bandage your eyes and you too can experience all this!

The point of this experiment to try and experience what people with disabilities go through is that it would still be a choice - you can try and stop when you've had enough, they can't. People with disabilities did not choose their disability and they can't choose to walk away from or ignore it.

It's very important to remember that physical accessibility benefits everybody visiting healthcare institutions, not just patients with disabilities. Older people in general, pregnant

women, and mothers with prams all prefer to use a gently sloping ramp or lift instead of steps. Similarly, access to information in simpler formats would be welcomed by many patients not particularly familiar with complicated medical jargon.

If people with disabilities are to participate in social activities on an equal basis with other members of society, then society and all its composite elements, including people working in healthcare, must contribute to reducing the hindrances and barriers put in their way.

All users of healthcare services, particularly in larger facilities, would benefit greatly from the existence of centralised information desks where patients could ask for information about the services on offer. People with disabilities could use such places to register their need for certain services or request information in specific formats.

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<sup>5</sup> Annex I  
<sup>6</sup> *ibid.*



# 3.

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## **General recommendations on how to approach and communicate with persons with disabilities**

Individuals with disabilities want and expect to be treated with the same consideration and have the same opportunities as other patients. They have a right to expect the same level of healthcare and access to healthcare services, regardless of the condition of their other capabilities. They have the right to demand and receive the same level of information and treatment as people without disabilities.

The main recommendations for improving communication

with people with disabilities are very like those for people without disabilities: be welcoming and appropriate, listen carefully to what the patient has to say, avoid premature assumptions and jumping to conclusions.

It is important that healthcare staff address their stereotypes and prejudices critically. This includes the idea that people with disabilities are to be pitied and that it is okay to behave towards them in excessively protective or mothering ways. Most people with disabilities don't want that.

**All individuals with a disability have a need to consider themselves equal and independent!**

Individuals with disabilities often visit the doctor with a companion. So do many people who have no disability, but prefer not to go to the doctor on their own for any number of other reasons. These may include wanting company or having a child and no one to leave it with. This does not mean the companion should participate in the medical examination or be called upon to assist their friend with a disability during it.

It is important always to address the person with a disability who has presented as a patient directly, regardless of the disability in question (e.g. even with deafness, blindness, wheelchair use, some other aid or assistive de-

vice, or a speech-related disability) and to ask whether they want their companion to be present during consultations and the examination.

**Avoid communicating with a person with a disability through a third party.<sup>7</sup>**

**Listen carefully to what the patient with a disability or the parents of children and young people with disabilities have to say and any advice or instructions they may be able to give about how to deal with them, since they know their own bodies, habits, and needs best.**

It is important to realise that speech difficulties, or indeed any other difficulties a person with a disability may have, are often entirely unrelated to their intelligence. Jumping to conclusions about this must be avoided at all costs.

**Always remember wheelchair users care about the health of their lower limbs, even if they don't use them for walking!**

<sup>7</sup> When dealing with individuals with reduced intellectual capacities, ask the patient for information, to the degree possible, given their intellectual capabilities, and then supplement it in more detail by talking to parents or guardians.

When dealing with patients with disabilities, it is important to use clear, simple language to explain things, particularly if they have to sign documents or consent forms. Dealing with patients with disabilities carefully and fairly ensures they understand and can give informed consent to medical procedures.

**Bear in mind that consultations with patients with disabilities may require more time to be allocated than standard consultations.**

Time and patience are key to successful communication generally, not just with people with disabilities. Some procedures and examinations simply last longer than normal, even when they do not involve patients with disabilities. Healthcare professionals need to be aware that examinations and dealing with people with disabilities will work better if they make sure enough time is made available. They should lobby within the health care system for this, as well as to have such demands built into the operating protocols in healthcare facilities. This will ensure neither they nor their patients are exposed to unnecessary stress because of insufficient time.

Enough time must be allowed for individuals with disabilities to describe their difficulties in detail, even when this means additional time.



**Some people with disabilities have developed a certain degree of expertise regarding their own specific problems. This should be respected. Healthcare professionals should ask patients about previous positive experiences in dealing with their problems.**

On the other hand, it also important to realise that some individuals will need more information and support to overcome their problems. This is particularly true of people who are only beginning to deal with a disability.

Healthcare staff should pay attention to the vocabulary persons with disabilities use to describe their own problems and use the same words in asking questions, if they want to arrive at valid results.

This recommendation is equally valid for any patients without a medical background or education. We wouldn't expect a mechanical or an electrical engineer to understand medical terminology.

**Healthcare staff should do their best to replace medical terminology and jargon with ordinary, simple, and easily understandable words. They should speak in concrete terms, clearly, and at a moderate speed.**

Studies worldwide have shown that people leaving a clinic are frequently not able to repeat what the doctor has told them. This is also true of some people with disabilities. It is never out of place for a doctor to run through the key points of most significance for the patient one more time after concluding the examination.

We do not recommend asking patients whether they have understood the instructions, simply because at that point they may well think they have, but it may not in fact be the case.

**After examination and diagnosis, the doctor should ask patients to repeat back what they should and should not do, explaining**

**that he simply wishes to check whether he has given the correct instructions.**

Patients with disabilities should be provided with explanations of anything that might be unclear and any questions they have should be answered. Before embarking on a medical examination, the doctor should explain what the procedure involves in the form of a conversation.

Where an examination includes physical contact or the use of instruments, the healthcare professional should make this very clear to the patient in advance.

It is important to ensure patients with disabilities have been fully informed of what an examination, diagnosis, or treatment involves and of any future activities or actions to be taken, so that they may arrive at as full an understanding of their own health as possible.

It is important to inform patients fully regarding the formal procedures for ordering orthopaedic and other assistive devices through the healthcare funds. It is vital that assistive devices be of satisfactory quality and well-suited to the patient's personal needs.



# 4.

## **Communicating with children and young people with disabilities**

In addition to these general recommendations, we have several specific suggestions on how to communicate with children and young people with disabilities.

Children are anyone up to 18 years of age, young people those aged between 18 and 30. Please note all recommendations for young people with disabilities apply equally to adults with the same disability, with due consideration is given to the needs or circumstances of the individual.

To make it easier to discuss the specific characteristics of communicating with children and young people with a given disability, at least in the context of this brochure, we will be applying the following categorisation, which is not based on

medical diagnosis:

1. Patients with physical or sensory disabilities
2. Patients with mild-to-moderate intellectual disabilities
3. Patients with severe to very severe intellectual disabilities
4. Patients with a combination of disabilities

**When communicating with children and young people with disabilities, it is always good to begin by addressing them by name, because they like to hear it, and then by presenting oneself to them.**

Look them in the eye and be sure to smile. In this way, you are acknowledging the existence of the child or young person with disability and indicating you will have PATIENCE, which is a key word for this type of relationship.

Questions you shouldn't ask when examining a child with a disability:

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- **Are you getting better, has there been any progress?**
- **Is your wheelchair good, do you need a new one?**
- **Do you go to the association for children with your sort of disability?**

Questions you should ask:

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- **Are you going to school, what class are you in, how are you doing academically?**
- **What's your favourite/least favourite subject?**
- **Do you have any brothers or sisters?**
- **Do you help around the house?**
- **What do you like to watch on TV?**

### 4.1.1.

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## Communicating with children and young people with physical or sensory disabilities

This section relates to kids and young people with exclusively physical or sensory disabilities, including primarily:

- **a physical disability** (cerebral palsy, muscular dystrophy...)
- **hearing loss** (deafness or hardness of hearing)
- **impaired sight** (blindness or impaired vision)

With children with physical or sensory disabilities younger than 12, healthcare professionals must cooperate with parents in communicating with the children, as they would with children without disabilities.

With children with physical or sensory disabilities aged between 12 and 18, direct communication between doctor and child/young person, without the presence of a third party, is acceptable, so long as due consideration is shown for the underlying problem of the child/young person and the forms of communication used are appropriate to their disability.

**See also chapters 5, 6 and 7, which deal with communication with adults with physical or sensory disabilities.**

Most visits to a paediatrician or family doctor by children and young people with a disability are because of health issues like a cold or a flu, rather than because of the disability. Healthcare professionals should focus exclusively on the current problem for which the patient is seeking assistance.

### 4.1.2.

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## Communicating with children and young people with mild-to-moderate intellectual disabilities and developmental disorders

Treating children and young people with intellectual disabilities and developmental disorders requires a good deal of attention and time. One major characteristic of communication between healthcare workers and children and young people with varying degrees of intellectual disability is the responsibility that lies with the healthcare workers to do their very best to ensure successful communication because of the reduced capacity of the patient to understand what's being said or to describe their own condition.

In any medical examination of an individual with reduced intellectual capacities or developmental disorders, communication will have to be partly with the child or young person and partly with the parent or guardian. The appropriate balance will depend on the degree to which the patient's capacities have been conserved. Where healthcare workers are not sure they can properly assess the patient's capacity for communication, they have a duty to request guidance from the parent on to what degree and how they should communicate with the child, on whether the patient is capable of expressing feelings, et cetera.

It is important for the doctor to address any child, young person, or indeed adult with reduced intellectual capacities directly and by name, as well as establishing contact through the use of gesture. It is important to realise that even individuals with the severest forms of intellectual disability are sensitive to vocal expressions of warmth and respond to smiling, touch, etc....

It is always desirable and often necessary for parents to mediate in communication on behalf of healthcare workers. This is particularly relevant for "young people" with mild-to-moderate intellectual disorders, because patients in this category, aged between 18 and 30, are in many ways comparable children aged between 8 and 14.

For some, though certainly not all, children and young people with certain syndromes, the difficulties are easily recog-

nisable and obvious and the doctor can develop a sense for them. For children/young people with intellectual disabilities or with various syndromes (Down or West syndrome) or children on the autistic spectrum, the medical model of defining the problem is satisfied with establishing a final diagnosis. Most further visits to a doctor for such a child or young person will be caused by colds or similar health problems. The doctor should treat them in same way as with any other child or young person.

Some children with these types of disability have a positive attitude towards doctors, particularly the paediatricians who have been monitoring their progress since birth. Some children, however, have a less positive attitude towards doctors. In these cases, a careful and informed approach to communication is required.

Some children do know how to tell a doctor about their problem and describe what is hurting them. Others have considerably more difficulty doing so.

Communication between parents and healthcare professionals is a very important part of a holistic interactive relationship. It can and should take place by telephone or email contact, even when the child is not receiving treatment. Information should be presented to parents of children and young people with intellectual disabilities in a careful and measured fashion, but it must not be unrealistic or involve "false hope".

Children in the autistic spectrum often don't have any physical disabilities or deformities and the child initially appears neuro-typical. There may be no formal diagnosis and the parents may not want one, as their child "presents as healthy". Autism manifests through a triad of symptoms: difficult and atypical communication, difficult or atypical social interaction, repetitive and compulsive behaviour (so called stereotyping). Disorders on the autistic spectrum are considerably more common in boys than girls (research suggests a ratio of 5:1, though experience in Bosnia suggests the ratio may be even higher here).<sup>8</sup> Given the fact that difficult/atypical communication with the external world is one of these three main groups of symptoms for the autistic spectrum, it is particularly important that healthcare workers exercise patience and invest additional effort in providing quality of service to children on the autistic spectrum. Unfortunately, little by way of general guidelines exists for communicating with such children, as each child is different and differently placed on the autistic spectrum, but the following recommendations should be followed, not least because they also help with other forms of disorder or syndrome:

**Be relaxed and express yourself calmly, avoid making sudden movements or noise while working, since most children have a low threshold of sensitivity to external stimulus.**

Be careful how you speak and what you say! Just because a child doesn't respond, doesn't mean he hasn't heard or understood.

**Show patience and avoid expressing disapproval if the child behaves inappropriately or is hyperactive. Ignore inappropriate behaviour by the child and try to concentrate on your task and to complete it in the shortest time possible.**

Whenever a child does what is asked of him, be sure to praise him ("you got it exactly right, high five"). When a child is not "obedient", then the parents should be advised to reward him for good behaviour. The healthcare worker can also reward a child, so long as the nature of the reward is agreed in advance with the parents. It is not a good idea to reward children independently, without consulting the parents first.

It is very important to establish effective communication with parents and to understand the "negative spiral" in how children on the autistic spectrum behave in response to their environment and their parents. If a doctor loses his patience, raises his voice, or expresses dissatisfaction, this will inevitably affect the parents' attitude. Children on the autistic spectrum are highly sensitive to such changes and can respond by becoming

<sup>8</sup> [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s\\_cid=ss6302a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w)



ing distressed, causing the parents additional discomfort. This can result in further crying, hyperactivity, or even screaming on the part of the child, causing the situation overall to deteriorate. It is therefore very important to help the parents to stay positive, calm and in a good mood from the beginning. That is half the job.

With children with Down syndrome, the doctor must make sure the child has heard and understood what is being discussed, regardless of how clearly or simply he may think it has been expressed. It's important to try and ignore any attention-seeking behaviour by the child or young person, while at the same time encouraging the preferred sort of behaviour.

Children with Down syndrome must be given time to formulate their responses and articulate their thoughts. Some children, including children with Down syndrome, understand things better than they show.

It is also important not to criticise the children for their behaviour, as they may not have heard what they were supposed to do. Therefore, it is important to ensure that children have heard and understood what was said to them. If there is still no response, it is important to remain calm and collected and to refrain from criticising the child's behaviour.

It is important, in offering the best quality of service, to attend carefully to the parents, who have much more information regarding the child, with whom it can be difficult to establish

proper communication in such a brief interaction. Parents must never be blamed for their child's behaviour or told that "the child will grow out of it", or that "he's just a bit spoilt" or that they are oversensitive.

### 4.1.3.

## **Communicating with children and young people with severe to very severe intellectual disabilities**

Children and young people with severe to very severe intellectual disabilities are, in most cases, dependent on someone else, whether a parent or guardian. Most such children or young people can speak only with great difficulty or not at all and communication with them tends to be difficult or even impossible. In such situations, communication with doctors is difficult and frequently takes place through parents and guardians.

For some forms of medical examination, it can be practically impossible to establish communication with such children and young people and complete the examination. This includes situations where there is a negative reaction to even the simplest instruments, such as a stethoscope, or to the activities undertaken by the doctor, regardless of how open the approach. Such children and young people will very often

have the same reaction regardless of how well-adapted the healthcare institution's premises are for their age group. In such situations, the parents may have to hold the patient's hand or some other body part to facilitate the examination. Such situations are uncomfortable for both the parents and the medical staff and can be traumatic for the children, even though they may not be able to say so clearly. For some children or young people with severe intellectual disability, treatment and communication may only be possible based on continuous, even daily communication between doctors and parents or guardians.

#### 4.1.4.

### **Communicating with children and young people with combinations of disabilities**

It is not uncommon for children or young people born with a condition of more severe mental disability to have a combination of disabilities or incapacities, where physical and/or sensory disabilities are also present. Particularly difficult cases involve a child or young person who simply does not understand or is not aware of his own behaviour and actions and so cannot state, put across, or in any way express what he wants.... In certain cases, in addition to everything else, the child or young person may also be blind or deaf, unable to

move, or sit upright or hold his head upright.... Consequently, there may be chronic disease or organ damage, rendering the problem even more complex.

In such cases, healthcare workers must be prepared to bring to bear all their knowledge and training, as well as patience and understanding. They must also always bear in mind that not just the patient, but the whole family has needs that go beyond what other patients have. In such cases, doctors and other healthcare professionals may represent the "final sliver of hope", the only "light in the tunnel"....

The number of disorders that can be combined is very large. In the experience of the associations whose members participated in drafting this brochure, the most common combinations amongst children and young people are cerebral palsy with any form of intellectual disability, cerebral palsy with sight or hearing loss, and muscular dystrophy with some form of intellectual disability. Children or young people with various forms of syndrome may also have other accompanying disorders: children with Down syndrome who are also on the autistic spectrum, children with Down syndrome with severe intellectual disabilities, et cetera.

Everything that has been said about communicating with children and young people with physical disabilities or other forms of intellectual difficulty naturally also applies to children and young people with combined disabilities.

In other cases, like children and young people with cerebral palsy and hearing loss but no reduction in their intellectual capabilities, communicating with healthcare workers is much the same as with wheelchair users or children with hearing loss.

The most troublesome situations involve children or young people with a combination that involves a severe intellectual difficulty and some form of physical or sensory damage, like, for example, cerebral palsy and severe intellectual disability or a combination of sight loss, severe intellectual difficulty, and other forms of syndrome...

For such children or young persons, establishing any form of communication with healthcare workers is very difficult and doctors often end up basing their communication exclusively on mediation by parents or guardians.

## 4.2.

### **Accessibility of healthcare services, procedures and facilities to children and young people with different forms of disability**

Continuous education for paediatricians and family medicine doctors on disability and how best to meet the needs

of patients with disabilities, particularly children, is extremely important, as is continuous coordination.

**Wherever possible, children and young people with intellectual disabilities, particularly those severe or very severe difficulties, should be examined in their own homes. The same goes for any medical tests required.**

Treatment should be adapted to the needs of the child (using syrups, rather than pills), and certain types of diagnostic examination should be conducted under general anaesthetic, where feasible and not counterproductive.

It is not uncommon for children with intellectual disabilities (regardless of severity) to experience forms of psychosis. This often results in some degree of depression at some point in adolescence. It can be very difficult to diagnose depressive conditions in such children or young people or to determine the appropriate therapy. It is not uncommon for doctors to prescribe sedatives for children with intellectual disabilities to calm them and, in their view, facilitate communication.

In the experience of the parents of children with intellectual disabilities who participated in preparing this brochure, most sedatives produce negative reactions in their children. They

tend to make them even more nervous and sensitive and can cause the situation to deteriorate.

It is vital that healthcare workers avoid approaching children with severe or very severe disabilities in terms that might be summed up as “well, it could hardly be worse than it already is”.

The parents of children with severe forms of disability must be informed of their right to stay overnight in the hospital with their child.

Where a child or young person with reduced intellectual capabilities or a patient suffering from epilepsy has a health problem that requires in-patient care, they must be given a bed in the appropriate hospital department for their ailment (gastroenterology, pulmonology, etc.), and not treated out of the neurology department.

Children from this category often have thin veins that burst easily, requiring the use of intravenous cannulation for infants, regardless of the child’s age. This facilitates the entire process for both the healthcare workers and the patients.

When prescribing orthopaedic aids for children and young people with intellectual disabilities, realistic assessment is vital to ensure that the assistive device is suited to the patient’s real needs. Expedients to be avoided include prescribing assistive devices on grounds of cost, current availability, or supplier preference...

No patient should be denied a second or third aid, if really needed.

While healthcare professionals must receive adequate training, it is equally important that healthcare facilities be adequately equipped and the right conditions be in place for offering adequate services to children and young people with problems (e.g. pulmonary x-rays for children who can’t sit or stand, etc.).

Finding an appropriate arrangement that protects parents who have to hold their children, for example, while taking x-rays and so are exposed to radiation would be a significant improvement over current practice.

Specialized equipment required for treatment of children and young people with disabilities must be supplied to hospitals (e.g. where paediatric units only have small beds with protective sides or cots).

Children who can’t sit or hold their heads upright should have protective railings to their beds, while those older than ten require full-size beds and, not infrequently, anti-decubitus mattresses. Hospital nightwear is impractical for patients who, because of paralysis, spasm, or other similar problems, cannot dress themselves and can lead to injury.

Hospitals must have appropriate bathrooms, which are accessible and adapted for patients with various forms of dis-

ability, including children and young people.

Healthcare workers should pay attention, in working with children and young people with various forms of disability, to indicators of potential abuse. Individuals with reduced intellectual capacities may not be able to recognise or prevent such abuse themselves or be able to tell or alert anyone about it.

Where possible, quiet relaxing music should be played in waiting rooms and clinics and the walls of such premises should be discretely decorated with children's drawings and figures from non-violent cartoons.

**Where children or young people with intellectual disabilities won't sit down, they should not be forced. Instead, their curiosity should be engaged, patiently, through play, with gestures, mimicry and body language, to create a relationship of partnership and not opposition.**

Healthcare workers should ensure adequate communication with parents during periods between appointments for treatment and check-ups (by text messages, e-mail, or telephone calls), as the effect of prescription drugs often requires continuous monitoring, particularly those used for treating epilepsy.

Thorough check-ups should be frequent and regular, not just

during primary education.

Healthcare workers should ensure parents are adequately informed regarding the need for and risks involved in vaccinating children with disabilities. They should keep records and, preferably, a register for children with disabilities and enter data or remarks regularly on any changes in their files. This is particularly important because such children's underlying diagnosis is often accompanied by another ailment (many children with severe or very severe disabilities also suffer epileptic attacks).

Doctors must not allow the severe condition of a child with disabilities to affect the quality of their care-giving (choice of treatment, diagnostic procedures, etc.), or deal with them as though "not worth fighting for". While such advice may seem unnecessary or impertinent, given that good ethics are to be assumed of any doctor who has taken the Hippocratic oath, practice and the experience of the parents of children or young people with disabilities suggests otherwise.

It is important that patients across the region have access to specialists, particularly paediatric neurologists, within a reasonable distance, as long journeys can be excessively tiring for children and young people with disabilities.

A programme of support services for parents should be planned and developed. It should include counselling that helps parents learn how to help their child and understand

and restrain their needs and helps mothers to protect their daughters from sexual abuse or to rein in their sons' sexual impulses towards them...

Another step that would significantly help the parents of children with disabilities would be to allow appointments to be booked in advance by telephone or email. This would also allow healthcare staff to prepare themselves for examinations. It is inadvisable to keep children with intellectual disabilities hanging around waiting rooms longer than necessary and healthcare workers should do their best to give such children priority, so that they are not waiting in line to see the doctor. Parents will not seek this themselves, out of politeness, but delays in waiting rooms can lead to problems of various sorts (nervous behaviour, difficulty adapting to the unfamiliar environment, uncomfortable seating positions for children already suffering physical difficulties...).

There is much to be said for healthcare workers asking parents, when arranging appointments, what their child likes to eat or play with, so that some trifle the child is very fond of can be procured in advance as a potential reward for good behaviour. Where that is not possible, we recommend reminding parents, so they can bring something suitable with them from home.

Some children are nervous around or frightened of doctors, particularly in lab coats. We recommend that doctors in medical centres remove their white coats to ease their communi-

cation and overall interaction with their young patients with disabilities.

Aside from remaining calm and patient, staff should carry out their examinations of patients with disabilities just as they would with any other child. We recommend they try not to break rhythm and try to carry out the procedure without pauses or repetition, as it is important not to lose time, particularly if the child is in a good mood.

It is an excellent idea for doctors to ask parents in advance if there is anything in the examining room that might capture the child's attention (a fan, telephone...) and so might be used, if necessary, as a diversion, or, conversely, should be removed if likely to interfere with the examination.

If the child becomes upset for any reason (becomes distressed because of a smell, sound, fabric...) and will not cooperate at all, then it may be best to suggest the parents take him outside for a short walk and come back later or on a different day.

Medical staff must not under any circumstances tell parents to bring their child back when "it has grown up a bit", "stops being so hyperactive", or "learns to talk", and it is not permissible to tell them to find a different doctor instead. It is important to remember that all children have better and worse days and there is no reason to suppose that every time will be a "bad day".

### 4.2.1.

## Dentistry services

It is well known that children, and some adults, are afraid of going to the dentist, so it should be no surprise if this is also true of children and young people with disabilities. The biggest problems with dentistry occur with children and young people with intellectual disabilities or with motor and spasmodic problems. Only a very few institutions in Bosnia and Herzegovina specialise in dentistry services for children, young people, or even adults with disabilities and even fewer for children with intellectual disabilities.<sup>9</sup> The number of paediatric dentists who have trained specially and are willing to work with children and young people with intellectual disabilities is very small.

Children and young people with severe or very severe intellectual disabilities require general anaesthetic, as this is the only way they can be subjected to any dental procedure. As there is a considerable difference between an ordinary visit to the dentist and placing a patient, who happens to be a child or young person with developmental difficulties, under general anaesthetic and subjecting them to an operation, the reality is that many children and young people with intellectual disabilities do not visit the dentist regularly. Moreover, it is clear that because of using a range of medical drugs and impeded oral hygiene, such children have a higher incidence

of rotten teeth, gum infections, and so forth. All these problems are associated with considerable pain, which children and young people with intellectual disabilities may handle and react to very variously. Because they have difficulty expressing themselves, some children will cry for days, while others develop various forms of aggression and self-harming behaviours. Such situations are very stressful for children and young people with intellectual disabilities and their families. The best way of dealing with such problems is to act preventively, where possible, but in the end the extraction and repair of rotten teeth cannot be entirely avoided.

The healthcare system should have at its disposal enough specialist clinics for children and adults with different intellectual and physical disabilities with staff trained in all areas of dental service, at which procedures can be carried out regularly under general anaesthetic.

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<sup>9</sup> See Annex I

### An example of good practice



There are very few healthcare institutions anywhere in Bosnia and Herzegovina, whether in the entities of the Republika Srpska or the Federation of Bosnia and Herzegovina or in Brčko District, that have the equipment or trained staff to offer dental services under general anaesthetic to children or young people with intellectual disabilities. It is therefore worth singling out the experience of the Holy Family Centre in Mostar, where dental services are provided to children with severe or very severe disabilities under general anaesthetic by a team of professionals (dentists, oral surgeons, anaesthetists) from Italy, with many years' experience of working with such children and young people. They are assisted in this work by the healthcare staff of the Holy Family Centre.

While this practice at the Holy Family Centre in Mostar has not been officially adopted by the healthcare systems of either entity or Brčko District, it may be considered to represent an example of good practice thanks to which the dental problems of children with intellectual disabilities are being addressed. This is confirmed by the more than 900 operational procedures, each preceded by a simple preparatory procedure. Patients have access to anaesthetists and other healthcare professionals with considerable experience in working with children with severe and very severe physical and intellectual disabilities, which allows their dental problems to be dealt with during a single procedure, followed by swift post-operational recovery.

### 4.3.

## Accessibility of information to children and young people with different disabilities

Children with different physical or sensory disabilities, whose intellectual capabilities are fully preserved, should be presented with information in the manner described above for the relevant disability.

If the child is non-verbal, images may be used. Some children can understand drawings or diagrams as representing certain types of information.

Use may also be made of the fact that many children on the autistic spectrum are fascinated by modern technology, so that information can be presented to them using computers or mobile phones.



# 5.

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## **Communicating with people who are deaf and hard of hearing**

There are also characteristics specific to communication with patients who are deaf or hard of hearing. It requires more time and for precisely this reason we will be dedicating considerable attention to it in this brochure.

When dealing with an individual who is hard of hearing, it is best to agree explicitly with them how they prefer to carry on the conversation and to reduce background noise to a minimum, e.g. by closing doors and making sure that there are no other conversations taking place in the room at the same time. Such measures ease communication with people who are hard of hearing.

There is no need to talk louder or make exaggerated facial

grimaces to get the meaning of your words over to someone who is deaf or hard of hearing. It is enough to talk slowly and ensure the patient has a clear view of the lips of the person talking, since most will be able to read lips, as this helps them in understanding the message. For this reason, it is important for a person talking to someone who is deaf or hard of hearing to keep his lips in the light and clearly visible.

**It is important to use short and clear sentences in talking with people who are deaf or hard of hearing and always to face them while talking so that you can see whether they have been able to follow what you are saying.**

If they indicate they have not understood what you are saying, you should try to rephrase it rather than repeat it. Not understanding the content of what is being said to them can be due to fact that people who are deaf or hard of hearing use a less diverse vocabulary.

If it seems likely to help communication, it is a good idea to use miming, body language and gestures.

It is particularly advisable in conversations with deaf people to check whether the meaning of the message has got through properly. The same is true in communicating with people who are hard of hearing or have speech difficulties.

Where a doctor or medical team know in advance that they will be seeing a patient who is deaf, the healthcare facility should provide a sign language interpreter. In some parts of Bosnia and Herzegovina, this is not a problem, as the patient's medical card or records include a special mark or note to the effect that the patient is deaf. This allows for sign language services to be arranged in advance.

Sign language is the official language of the deaf community in Bosnia and Herzegovina and healthcare institutions should have a list of registered interpreters. These lists can be provided by the associations of deaf people and healthcare institutions should plan and allocate funds for the purpose.

**It is important for healthcare professionals to remember always to address patients who are deaf directly and maintain eye contact with them, regardless of whether there is a sign language interpreter or family member mediating the conversation.**

Where such services cannot be procured, then recourse may be had to pen and paper, to establish communication by writing or drawing. Illustrations or other visual aids, like images on a computer or a model of body parts that can be handled, can aid in communication.

In any case, healthcare staff should allocate enough time to ensure that patients who are deaf enjoy an adequate level of healthcare. It is important that the patient not feel under pressure or rushed while describing his problems.

All the recommendations contained in this brochure regarding communication with deaf adults also apply to communication with children and young people with the same disability.

## 5.1.

### **Accessibility of healthcare services, procedures and facilities to people who are deaf or hard of hearing**

Before they can even begin communicating as part of a medical examination, patients who are deaf or hard of hearing have first to negotiate access to healthcare services. The ability to make appointments by text message would help greatly in this regard, as most deaf people do use mobile phones.

Once a patient who is deaf has turned up for an appointment, it is important to explain how they will be notified that it is their turn to enter the doctor's office. One possibility is for a member of staff to bring them there personally, another is a pre-arranged hand signal, a third is a piece of paper with their name on it.

When taking x-rays, it is important to provide the patient with clear and simple instructions in advance of what is required of them, where and how to stand and what to do. Patients should not be treated like "dolls" to be moved about by medical staff in front of the x-ray machine or be given spoken instructions like "Breathe in!" or "Hold your breath!" from outside of their line of sight.

When a patient is accompanied by a sign language interpreter, then arrangements as to how best to carry out the x-ray can be discussed with the interpreter. The procedure could be simplified by introducing coloured signs to be used as agreed between the medical technicians and the patient.

When carrying out an ultrasound on a patient who is deaf, they should be told in advance how to turn and what position to take to ensure the procedure is a success.

It is equally important to look for the best way to ensure success when using a stethoscope in an examination. The doctor should not expect the patient to breathe deeply on a spoken command, if the patient's back is turned towards him. The reason is simple. The patient can't hear the doctor.

The use of protective facemasks is a significant obstacle to communication between doctors and patients who are deaf or hard of hearing. It would be helpful for medical staff to restrict the use of such masks as much as possible with such patients, as they naturally prefer to "hear" what their doctors

have to say about their health directly from them, looking at a face, or rather lips that are not hidden behind a mask.

## 5.2.

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### **Accessibility of information to the patients who are deaf or hard of hearing**

General information about patients' rights and the services available to them should be available in written form and simple language. Care is needed in this regard as deaf patients may have a relatively limited vocabulary.

The screens used in healthcare facilities for advertising could also be used to present other forms of content, including information on patient rights in sign language.



# 6.

## **Communicating with individuals who are blind or visually impaired**

A doctor must always introduce himself when examining a patient who is blind and should never assume the patient will recognise his voice, no matter how many times he may have heard it. It is important to use your full name and to explain your role and task in the room, after which, anyone else present should also be introduced and their roles explained (nurses, medical students, etc.), so that the patient knows who is present at the examination and why.

**When a patient who is blind has an assistant or companion, it is important first to check whether they agree to that person being present during all phases of the consultation or examination. This should be applied as a rule in examining persons with disabilities.**

Communication with a patients who are blind should not take place through a third person, any more than with a patient with any other form of disability. They should always be addressed directly, naturally, and clearly. Losing your sight does not entail hearing loss.

Where the patient is not wearing dark glasses, it is important to remember that a lack of eye contact does not mean a lack of attention to what is being discussed.

If other staff members have to be introduced into the examination room, the patient should be told in advance who is entering the room and why.

**When a doctor has finished with the discussion and is ready to leave the room, he should say so explicitly, so that the patient is aware that he is no longer present or that one of the participants in the conversation has left.**

It is important to ensure quiet conditions during examination, with no background noise, as this can affect a blind patient's ability to focus on the conversation.

**Freely use everyday speech in communicating with patients who are blind. There is no need to avoid words like “let’s see” or “see you again”.**

As with all patients with disabilities, patients who are blind should be told when a conversation will be followed by a physical examination.

It is important to be precise in giving them instructions to blind patients and to be clear, e.g. as to what side the door is on.

As with all patients with disabilities, patience is needed with blind patients and adequate time allocation must be allowed.

All the above recommendations regarding communication with patients who are blind apply equally to children and young people with the same disability.

## 6.1.

### **Accessibility of healthcare services, procedures and facilities to individuals who are blind or visually impaired**

To ensure healthcare services are accessible to patients who are blind, staff should be properly introduced to basic techniques for guiding them.

If a blind patient is not familiar with a given environment, they should be asked politely if they would like to be brought to their destination. If they refuse, offense should not be taken.

Patients who are blind should always be asked if they need help, for example, when they have to find their way to another department in the facility. In such cases, a member of staff should be available to provide such assistance, when the patient does not have their own assistant.

**It is important for anyone offering to help or escort someone who is blind to understand that it is enough to extend an arm so that the individual being assisted can take their elbow or shoulder. It is never okay to grab a patient's hand and pull them by the hand!**

When leading a patient who is blind, it is important to walk slowly beside them, at a moderate pace. When there are steps or some other obstacle, it is important to tell the patient whether this involves going up or down, left or right. Similarly, it is important to let them know when they have reached a flat surface.

**One should never push a patient who is blind to sit on a chair. The right approach is to describe where the chair is located and to guide their hand to the chair's back or arm, allowing them to orient and seat themselves in the chair.**

It is very important for the doctor to explain and describe the layout of the room and things in it before conducting the examination, to give as good a picture as possible of it and so that the patient knows which way to turn or move, should it be required during the examination. Here, clear and precise instructions are important. The so-called clock is useful for this form of communication ("Raise your arm to three o'clock!").

Healthcare staff should always be mindful of the fact that a change in the intensity of light can affect vision – strong sunlight can be a bigger problem than dark corridors for people with impaired vision, so that rooms should be darkened and the patient's back should be turned to any source of light. Tactile floor surfaces and stark contrast between colours on

floors and walls can help patients with impaired vision get around healthcare facilities.

If there is fixed equipment on or around chairs, couches or equipment that is to be used during a medical examination, their position should be described to any patient who is blind, again using the clock method: “there is a coatstand at 3 o’clock”. The patient should also be told what the item in question is, to avoid them being caught unawares, hitting or hurting themselves or damaging it.

When conducting an x-ray, care is required to provide clear instructions in advance, as with patients who are deaf or hard of hearing. The patient should be told clearly where and how to stand and what, if anything, they will be asked to do to ensure the x-ray is properly taken.

If there is a need for a patient who is blind to get into a vehicle, e.g. an ambulance, the vehicle doors should be opened and the patient’s hand placed at the top edge of door. This will allow them to orient and seat themselves in the vehicle.

**Care is required to ensure that there is nothing affixed to hallway or waiting room walls in healthcare facilities that protrudes more than five centimetres and that a patient who is blind will not be able to identify by using**

**his white cane. Otherwise, he may bump into it and hurt himself and any such unexpected blow can cause significant disorientation.**

## 6.2.

### **Accessibility of information to individuals who are blind or visually impaired**

All essential information on healthcare services offered, from the layout of the facility and location of services to preventive programmes presented through public information campaigns to general information on patient rights and services available through the public healthcare system, should be made available to patients who are blind in Braille or in large print. The availability of such information in audio formats would be welcome.

Where patients who are blind have access to computers that have been adapted for their use, some information can be sent to them as email, whose content they can access using computer programmes for reading text.



# 7.

## **Communicating with individuals with physical disabilities**

Communicating with individuals with physical disabilities, which includes wheelchair users and people with independent motility with or without the help of aids (canes, crutches, walking frames), as well as people with damaged upper limbs, requires little more than the effort required to sit down while talking with a wheelchair user.

All the recommendations contained in this brochure regarding communication with adults apply equally to communication with children and young people with physical disabilities.

## 7.1.

### **Accessibility of healthcare services, procedures and facilities to individuals with physical disabilities**

Where a patient with a physical disability has not made an appointment for a medical examination in advance, healthcare staff should ask whether they need to be examined without waiting their turn, particularly in institutions without accessible toilets.

Individuals with physical disabilities can have normal sexual and reproductive lives. They should be encouraged to do so and provided any necessary guidance, including explaining the importance of taking care of their reproductive health.

The most important precondition in providing healthcare services to individuals with physical disabilities is to avoid unnecessary physical barriers to access. All patients benefit when healthcare facilities are laid out in accordance with the principles of universal design, but those with physical disabilities benefit particularly. A simple example is doors that can be opened using a closed fist without major physical effort.

**From the above, it follows that it is very important to ensure all units in a facility are accessible. If only one clinic is, then all examinations should be arranged in that accessible clinic, where and when possible.**

In developed countries, wheelchair-using patients are not usually examined in their wheelchairs, as the starting point is always what works best to ensure the highest quality of service, just like with any other patient. It is well established that a medical examination conducted in a wheelchair is never as thorough as one on a couch or table designed for the purpose.

For this to be feasible, adjustable height examination tables must be available.

Naturally, where only examination of, for example, the face is required, then the wheelchair user may remain in their chair.

Where healthcare institutions do not have accessible equipment, adjustable tables, or lifts for patients, then the number of trained staff must be sufficient to ensure patients are not denied medical services.

Even when a patient who uses a wheelchair or other aid is

accompanied by a family member or friend, those accompanying persons are not necessarily there to assist the patient prepare for examination or to assist during the process.

The healthcare provider must offer the patient reasonable assistance in certain activities, including getting dressed and undressed, getting on and off the examination table, settling into a recumbent position, keeping their balance while being examined...

Healthcare facilities must also look after their own staff and protect their health, which can suffer from having to lift patients in and out of wheelchairs onto the examination table or carrying out other actions that would be done more quickly and safely with the help of a hoist for use with patients with disabilities who do not have the use of their lower limbs.

It is a lot easier and safer to train staff to use such equipment and how to position individuals with disabilities properly than to expose them and the patients to unnecessarily unpleasant experiences.

## 7.2.

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### **Accessibility of information to individuals with physical disabilities**

Individuals with physical disabilities, but no other difficulties, have no special needs for information accessibility.





# 8.

## **Communicating with persons with mental disabilities**

Individuals with mental disabilities vary greatly depending on the type of ailment or mental disorder.

**One should bear in mind that individuals with mental or psycho-social disabilities have often had specific experience of stigmatisation and highly unpleasant and traumatic experiences of treatment.**

Individuals may display a certain resistance to or fear of healthcare staff. The best way to alleviate this fear is through respect, particularly as such individuals are not

normally on the receiving end of respect even in their own environment. Like other patients, they can feel scared, nervous, and confused.

Communication with individuals with mental disabilities requires considerable patience, an even tone of voice, a willingness to repeat oneself when required, and, most importantly, careful listening. As with other patients, with individuals with disabilities, it is the patient who should be addressed, not any accompanying person.

A very widespread problem reported by persons with psychosocial disabilities relates to negative treatment by healthcare workers and the vocabulary they deploy in communication. Patients are treated as less than equal participants in communication (polite plural forms are not used, the tone used by healthcare staff to address them is commanding and raised). Nor should one lose sight of the fact that the media and public often write and talk about people with mental illnesses in sensation-alistic terms as violent individuals.

**Not even healthcare professionals are free of prejudices, so that they sometimes act as though their primary task is to protect society and the family and not the health of the patient.**

## 8.1.

### **Accessibility of healthcare services, procedures and facilities to individuals with mental disabilities**

During any medical examination, the patient should be properly informed as to what is being done. Any physical contact should be flagged in advance.

**Most family medicine practitioners are too focused on the mental health of the patient and often ignore physical symptoms. This can have a negative impact on the health and life of the individual. Patients are often referred by their primary healthcare provider to a psychiatric department, even when they have reported somatic symptoms. Psychiatrists are not equipped to treat such problems. This approach has an additional deleterious effect on mental health and self-stigmatisation.**

Healthcare staff should refer individuals with mental disabilities to the department that treats their current health problem, as is done for patients without mental disabilities.

There may be intellectual disorders present, but that is the exception, rather than the rule. Most people with psychosocial disabilities are themselves concerned about their health and that includes taking any prescribed treatment. Healthcare staff need to make the time to educate family members of patients with mental disabilities regarding their patient's condition, as well as of the importance of independence and personal care for their own health.

Moreover, healthcare professionals should always pay due attention to any potential complications or side-effects (contraindications) of drugs their patient has been prescribed.

## 8.2.

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### **Accessibility of information to individuals with mental disabilities**

Individuals with mental disabilities but no other difficulties do not need information to be made accessible in special formats. Like many other patients who do not have disabilities, they would be more receptive to some types of information if presented in a simpler format and **written in simpler language.**





# Annex 1.

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Monitoring was carried out over two months, from December 15, 2014, to February 15, 2015, of the accessibility of healthcare facilities on the territory of the five regions in Bosnia and Herzegovina in which the five coalitions of organisations of persons with disabilities with which MyRight cooperates on the implementation of programmes to build the knowledge-base and skills of persons with disabilities operate.

This monitoring was carried out by field coordinators representing the five abovementioned coalitions who themselves have disabilities. They made field visits to healthcare institutions, which involved filling out questionnaires in situ. Representatives of all five coalitions were involved in drafting the questionnaire.

The questionnaire comprises 50 questions covering all forms of accessibility, from the external, environment, and physical aspects of the building to its internal features, including physical access, parking, the presence of a wheelchair ramp erected in line with building standards, lifts or platforms to allow access to upper storeys, the existence of bathroom facilities

for persons with disabilities and the application of universal design inside the facility.

The questionnaire also contains questions regarding the accessibility of specific services targeted at persons with disabilities, including gynaecological services for women with disabilities or dentistry services for children with intellectual disabilities.

Several of the questions related to the existence of legal regulations and how well-informed staff were as to the rights of individuals with disabilities and the policy of inclusivity and accessibility for individuals with disabilities, or of the actions required in cases of emergency or exceptional circumstances. Answers to these questions were gathered from the employees of healthcare facilities.

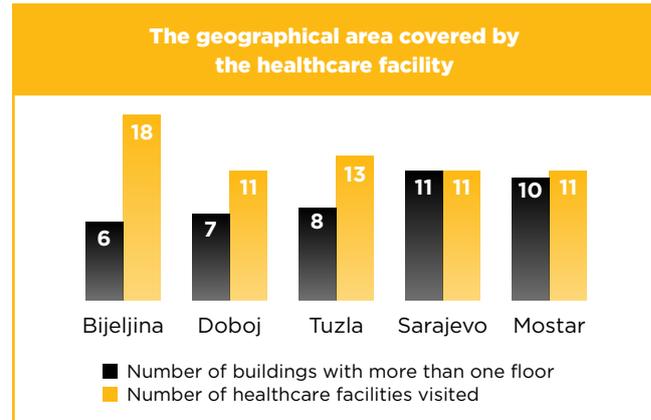
Each field coordinator visited one hospital department and ten community medical centres or family medicine centres, taking care to keep the sample balanced between urban and rural parts of the region.

In the end, some 64 facilities were visited, with field coordinators at the hospitals in Tuzla and Bijeljina visiting multiple units each.

The results of the survey indicate that not one of these 64 institutions was fully accessible to individuals with disabilities. Since persons with disabilities are a diverse group, accessibility may be viewed from various perspectives, from physical

access to the facilities for wheelchair users or those dependent on other forms of mobility aid to the accessibility of information about the facility and its services to persons with sensory disabilities like deafness or blindness.

In conclusion, many different actions and activities are required to improve the situation and ensure persons with disabilities enjoy equality of opportunity with other citizens, at least with regard to healthcare services.



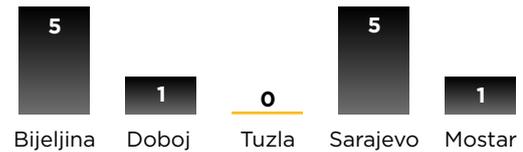
## Physical accessibility of healthcare facilities

All numerical data represent positive answers to questions from the questionnaire.

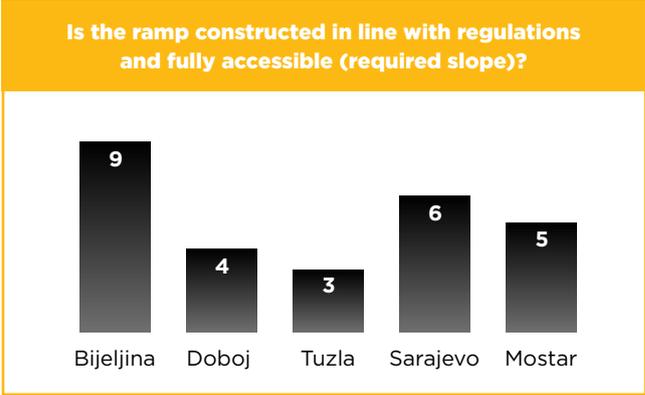
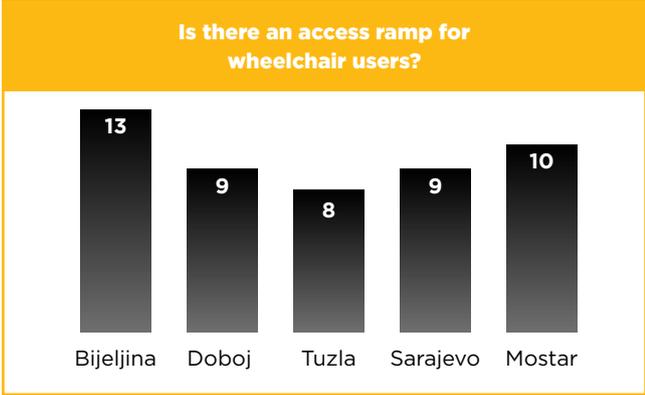
Are the parking spaces reserved for persons with disabilities wide enough to allow wheelchair users to get into and out of the car?



Is the path from the parking area to the building suitable for use by persons with disabilities?

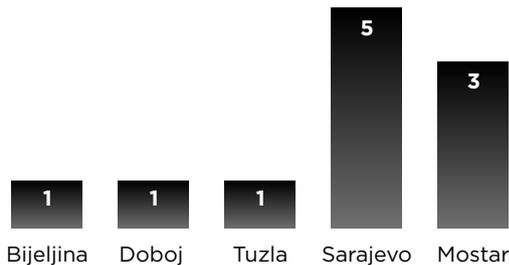


Several relatively minor actions required to improve parking facilities for persons with disabilities have been identified, from clearly marking spaces and locating them as closely as possible to the building to ensuring they are connected with the building by an appropriate and usable path, with no holes or steps, pillars or containers in the way or on adjacent buildings, as they can, for example, represent a hindrance to individuals who are blind.



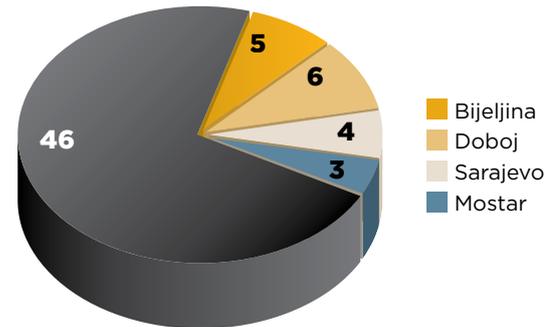
Quite a few multi-storey institutions do possess a ramp for wheelchair users. The following graph indicates, however, how few of these ramps have been constructed properly.

**If the facility is in a multi-storey building, is there a lift?**



Fewer than half of the multi-storey buildings visited had a lift and there were cases of institutions that had a ramp to allow persons with disabilities to enter the building, but only to access the ground floor. There are many cases where special services are upstairs, so that individuals with disabilities have to be carried up several floors, which is neither pleasant for the individual involved, nor easy for those doing the carrying. In certain cases, the specialists are willing to come downstairs to conduct their examination, but this is hardly the optimal solution.

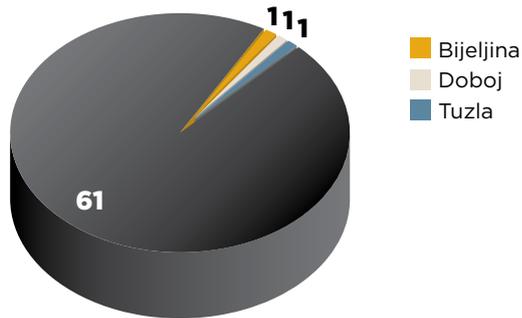
**Does the institution have a toilet that is accessible to persons with disabilities?**



Of the 64 facilities visited by the field coordinators over the two-month period, toilet facilities that were accessible to wheelchair users were recorded in only 18.

## Accessibility of healthcare services

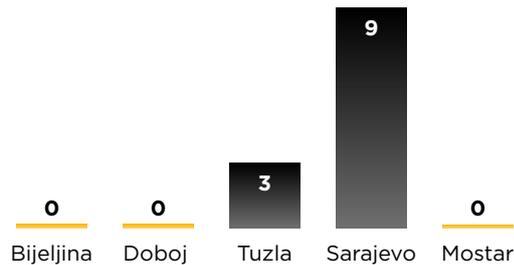
Does the option exist of offering dental services to persons or children with intellectual disabilities?



This question was asked in the dental clinics belonging to healthcare institutions visited to assess the accessibility of their facilities in cases where general anaesthetic is required, as is generally the case when dealing with patients with intellectual disabilities or motor or spasmodic difficulties. Clearly, most clinics cannot offer such services, because they do not have an anaesthetist or surgeon or the other conditions required for administering a general anaesthetic.

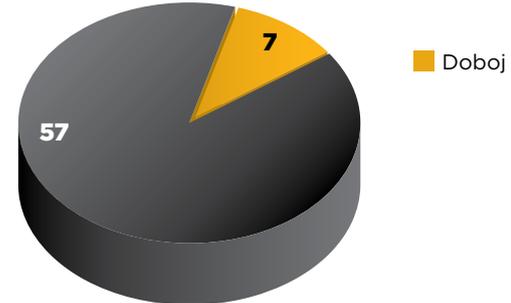


### Is there a gynaecological chair available that is suitable for women with disabilities?



Only three of the six healthcare facilities with gynaecological departments visited in Tuzla had a chair whose height could be adjusted. In Sarajevo, all nine did. Six of these nine, however, are upstairs in buildings that are inaccessible to wheelchair users, as there is no lift.

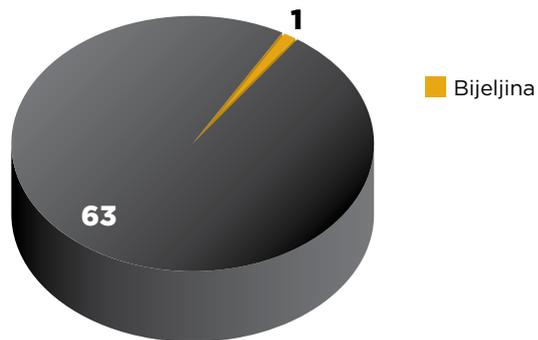
### Can people who are deaf make appointments by text message?



Appointments cannot be made by text message in the institutions surveyed in Bijeljina, Tuzla, Sarajevo, and Mostar.

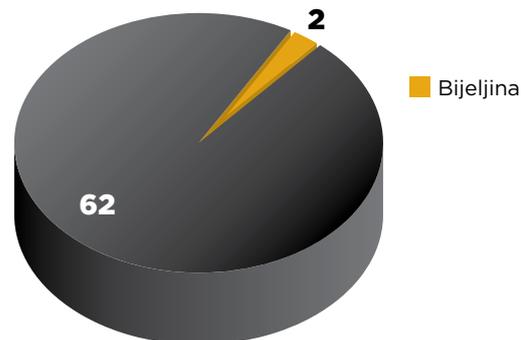
This possibility is available in seven healthcare facilities in Doboj, but nowhere else.

**Is information on prevention and treatment offered in forms that are accessible to patients who are blind or deaf?**



This service is not available in 63 of the institutions surveyed.

**Do medical staff have access to a sign language interpreter?**



In fact, the service is only available in Bijeljina.

Information on the services offered by the facilities is not available in a form that might, for example, be accessible to persons with blindness. We are not referring to hundreds of copies of a notice or materials on prevention or treatment prepared in Braille or larger font, but just a couple of copies that could be made available while the patient is on site and which would remain in the facility. This should not be a problem. It is an example of reasonable accommodation and is to be found in only one institution, in Bijeljina.

Two institutions in Bijeljina offered positive examples, as there were nurses on staff who had completed training in sign language and had equipped themselves for communication with individuals with deafness or impaired hearing.

## Familiarity with the rights of persons with disabilities and how to treat them

Have healthcare staff had any training on the rights of persons with disability or how to treat them?



*Fortunately, now you have this brochure!*



# #PonosniNaSebe

**FIGHTING FOR A JUST SOCIETY, EQUAL OPPORTUNITIES AND EQUAL PARTICIPATION IN SOCIETY FOR PERSONS WITH DISABILITIES**



Swedish International Development Agency (SIDA)



has been supporting MyRight's work in Bosnia and Herzegovina.