## EBU TOOLKIT



# Implementing standards for LOW VISION SERVICES in Europe



#### **EDITORIAL**

This EBU toolkit for low vision services is the outcome of the low vision activity in 2015, that was part of EBU's project *REC15-Act 3.4.* It is the follow up on the brochure on EBU minimum standards for low vision services in Europe that was published December 2014.

Text: Birgitta J. Blokland, coordinator EBU project on Standards for low vision services in Europe

Toolkit lay-out & design: DUD

Pictures (© holders): Soffis textbyrå, ArtCo, Juha Seppälä, NIH-national eye institute, Sight Savers International, Harry Geyskens, EBU archive

Photo-editing: ArtCo

This EBU toolkit for low vision services in Europe is produced in accessible electronic format and is available from the EBU website <a href="https://www.euroblind.org">www.euroblind.org</a>

© Copyright EBU - December 2015

Full credit must be given to EBU when reproducing or otherwise using (part of) the text contained in this publication.

Permission must be obtained from EBU before using any of the photos contained in this toolkit.

#### **EBU Office:**

6 rue Gager-Gabillot, 75015 Paris, France

Tel: +33 1 47 05 38 20 | Fax: +33 1 47 05 38 21

E-mail: <a href="mailto:ebu@euroblind.org">ebu@euroblind.org</a> | website: <a href="mailto:www.euroblind.org">www.euroblind.org</a> | EBU is a registered charity under French law, 105073P.



This EBU publication is supported under the Rights, Equality and Citizenship programme 2014-2020 of the European Commission.

The information it contains does not necessarily reflect the position or opinion of the European Commission.

### **CONTENTS**

Introduction				
Implementation of EBU standards for Low Vision services in Europe9				
Standards and tools	11			
1. Rights-based	11			
2. Personalised	15			
3. Assessed with Nine-Plus parameters	18			
4. Well-designed programme	22			
5. By a team of properly trained, highly skilled professionals	25			
6. On time and ongoing	29			
7. In accessible & easy-to-reach facilities	31			
8. Free of charge or at low cost	35			
9. Raising awareness	37			
10. Prevention and early detection	40			
Useful links	42			
Terminology	46			

### INTRODUCTION

#### **BACKGROUND**

There are more than 30 million blind and partially sighted people in geographical Europe. And with the growing population of elderly, this number will only increase in the coming years.

The vast majority of people with sight loss has low vision or partial sight, two terms for the same condition that are used throughout this toolkit.

Low vision or partial sight is a condition in which vision cannot be fully corrected by glasses, contact lenses, surgery or medicine. Having low vision means that, despite treatment or glasses, participating in daily activities and performing everyday tasks are difficult. For instance, reading the mail, writing, shopping, cooking, watching TV, recognizing faces, going out and about (orientation and mobility). This also affects one's functioning and quality of life.

There are many different causes for sight loss that can affect children and adults of all ages, however women are at higher risk than men. Some examples are: Glaucoma, Macular Degeneration, Cataracts, Retinitis Pigmentosa, Albinism, Diabetes, a tumor, eye-injury, and side-effects of medical treatment. Irreversible sight loss is also highly age-related and common among people over 65.

Low vision is not always visible, and therefore a disability that is often not understood. Individuals with partial sight can have very different amounts of vision and ways of seeing and therefore have very different

specific needs for support and rehabilitation services that have to be met in a personalised and holistic way.

Someone whose vision is deteriorating, needs comprehensive rehabilitation at the earliest possible stage. Support, training, aids and services must be available to them free of charge, or at low cost, and meet individual needs and circumstances, based on an assessment of functional low vision with both functional and medical parameters. Local provision of low vision services by properly trained, highly skilled low vision professionals in accessible, easy to reach facilities, is equally important to adequately help and support all those affected by low vision to live independently, to maintain their activities and to take part in society.

Yet, the results from the EBU survey held in 2013 amongst its 44 national member organisations, show that low vision rehabilitation and support services differ significantly between EBU countries. Some have excellent, high quality services available to anyone with a need for support. In other countries, low vision services are not available to all with sight loss, and in over one-third of EBU countries, no specific low vision services exist. This means that the majority of people with sight loss is excluded from the adequate low vision support they need and have a right to. Support that enables them to live independently and to participate actively in social, economic, political and cultural life.

This fact calls for urgent action from all stakeholders to aim at bringing low vision services to a high level in Europe and to ensure that all

persons with different levels of sight loss can enjoy their right to rehabilitation services, in compliance with the UNCRPD.

#### **EBU STANDARDS AND TOOLS**

As part of its plan of action 2011-2015, EBU developed a set of standards for low vision services in Europe, based on the outcome of the survey on low vision services, on good practice examples in EBU countries, and on the low vision work undertaken by EBU over the past twenty years.

For the purpose of providing a resource document for the implementation of the EBU standards for low vision services in Europe, EBU produced this toolkit 2015/2016. The toolkit with examples and references may be found useful when undertaking action nationally to promote and lobby for establishing high level low vision services that are available and accessible to everyone with sight loss in need of support.

Whether this toolkit is simply used as a checklist, or to improve current low vision services in your country, or to support your actions and campaigns to create specific low vision rehabilitation and support services, let it inspire you to bring low vision services to a high level and to enable all partially sighted persons to enjoy their right to comprehensive rehabilitation and services, based on the UNCRPD.

#### **Dynamic toolkit**

It is impossible to include all the good information that is out there. The toolkit offers a selection, a sample of available resources. However, more tools can be added any time, so do let us know if you have resources that you think should be added to the toolkit! Mail your suggestions to the EBU office via <a href="mailto:ebusecretariat@euroblind.org">ebusecretariat@euroblind.org</a> and we will update the toolkit with your contributions.

#### **EBU & WHO**

As you will see mentioned further on, EBU is involved in the WHO process of developing standards for low vision rehabilitation, whereby the EBU standards have been submitted and taken on board. Updates on this WHO work can be found on the EBU website under latest news and under the low vision section.

#### **JOINT EFFORT**

EBU brings together a wealth of expertise on low vision and blindness and its impact on the daily life of millions of Europeans. Through our network of 44 countries we can share that expertise and good practice to work equally for blind and partially sighted people of all ages and both genders, to protect their rights and promote their interests and make us truly the united voice of the more than thirty million blind and partially sighted people in geographical Europe. Our large network can make that happen, joining forces and sharing responsibilities.

We can make a difference also in this joint effort of ensuring that good low vision services are available to people with different degrees of visionloss affecting their daily functioning. With those services the limiting impact of sight loss can be reduced and the quality of life improved. With your commitment and support, thist can be achieved - and we count you in!

EBU low vision team February 2016

#### **READ MORE**

The <u>brochure with the minimum standards</u> for low vision services in Europe and the toolkit are both available from the EBU website under the rehabilitation section, where you can also find relevant documents on rehabilitation and vocational training and rehabilitation for elderly people. Visit the low vision section for additional relevant documents: <a href="http://www.euroblind.org/working-areas/low-vision/">http://www.euroblind.org/working-areas/low-vision/</a>

### IMPLEMENTATION OF EBU STANDARDS FOR LOW VISION SERVICES IN EUROPE

Promotion and lobbying on national level for the implementation of the EBU standards for low vision services in Europe are based on the UNCRPD: The right to adequate support and rehabilitation services for both blind and partially sighted women and men of all ages.

National member organisations adhere to EBU's objectives, principles, and commitment to work equally for both blind and partially sighted people of both genders and all ages, with or without additional disability.

Therefore, EBU member organisations are to include low vision in their policies, strategies and activities to protect the rights and promote the interests of both blind and partially sighted people in Europe and in their country, and will:

- Take the necessary action to promote and implement the Minimum standards for low vision services in Europe;
- Raise awareness about low vision and its impact on daily life;
- Include low vision needs when promoting and lobbying for accessible information, goods, services and the built environment;
- Support prevention and early detection programmes

- Promote and lobby for a national eye-care plan that includes both blindness and low vision care and rehabilitation that meet individual needs as part of national health care program and social security system;
- Cooperate with rehabilitation service providers, monitoring and supporting programmes; Participate in national VISION 2020 initiatives;
- Promote the ratification and implementation of the UNCRPD.

Visit the EBU website for more information, background papers and useful links: <a href="http://www.euroblind.org/working-areas/low-vision/">http://www.euroblind.org/working-areas/low-vision/</a>

The full text of the UNCRPD article 26:

http://www.un.org/disabilities/convention/conventionfull.shtml

#### STANDARDS AND TOOLS

#### 1. RIGHTS-BASED

#### **STANDARD**

All persons with sight loss of all ages and both genders have the right to adequate rehabilitation and support services. This means that also comprehensive LOW VISION services must be available and accessible to everyone with a condition affecting functional vision. Whether a person has moderate or severe, or another form of low vision, the functional abilities in daily life activities are affected. Without to adequate, specific and personalised rehabilitation and support services, reduced functional vision has an unnecessarily higher disabling impact affecting a person's quality of life.

Yet in one third of EBU countries no specific low vision rehabilitation and support services exist. Most of these countries only offer rehabilitation for blind persons and those with severe low vision, excluding the majority of people with low vision from the services they need.

Other countries do have good, specific low vision services for anyone with sight loss facing difficulties in participating in daily activities and in performing daily tasks.

In EU countries all residing EU citizens are entitled to receive these services. Yet in practice, in some of EBU's countries, EU citizens residing are denied the access.

Those with sight loss in need of rehabilitation and support services, who are in a process of obtaining citizenship or residence permit, should be considered for eligibility. The need and urgency should prevaill to prevent further unnecessary deterioration of functioning. In our current age of refugees in Europe, this is a factor to keep in mind and act upon.

#### **TOOLS**

In EBU countries where good and high level low vision services are provided, in practice, legal residents with different degrees of functional vision loss, regardless of nationality, age or gender, have the right to and receive the low vision services they need. This should be available in all EBU countries.

1-EBU protects the rights and promotes the interests of blind and partially sighted women and men of all ages in geographical Europe. In all its activities the UNCRPD is one of the guiding documents.

2-<u>UNCRPD</u> Article 26.1: 'Habilitation and rehabilitation: "States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes,

particularly in the areas of health, employment, education and social services."

- -UNCRPD preamble i: Recognizing further the diversity of persons with disabilities.
- -UNCRPDaArticle 3 General principles.

3-EU charter of Fundamental Rights and non-discrimination (Lisbon treaty 2009) Title III - Equality - Article 26 - Integration of persons with disabilities)

4-WHO on rehabilitation: 'Rehabilitation and habilitation are instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently, and participate in education, the labour market and civic life. Access to rehabilitation and habilitation can decrease the consequences of disease or injury, improve health and quality of life and decrease use of health services.'

5-WHO on disability: 'Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction

between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. People with disabilities have the same health needs as non-disabled people – for immunization, cancer screening etc. They also may experience a narrower margin of health, both because of poverty and social exclusion, and also because they may be vulnerable to secondary conditions. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings.

6-Vision 2020. The global initiative Vision 2020, the right to sight includes low vision care among the five globally identified disease controlled priority areas, whereby rehabilitation is linked with both social and health care. http://www.who.int/topics/disabilities/en/

7-WHO is currently developing a standard for low vision rehabilitation and support services, also using the UNCRPD as basis. EBU is involved in this process. Updates will be published on the 'latest news'- section on EBU's homepage <a href="https://www.euroblind.org">www.euroblind.org</a>.

#### 2. PERSONALISED

#### **STANDARD**

Different forms of low vision require different solutions. Individual needs and circumstances must be met. Whether a person experiences low vision from birth or early childhood, or later in life is also a factor to take into consideration. And obviously the needs of a child differ from those of a (young) adult or senior.

A personalised programme is best to adequately and most effectively meet each individual's service and support needs in various areas of daily life activities in home, school, work and leisure settings. Personal, functional and environmental factors, as well as other factors, influence the needs and therefore a holistic approach and the use of ICF based instruments, based on function, are important to identify personal priorities and potential.

#### **TOOLS**

1-<u>UNCRPD</u> article 26.1.a: 'Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths.'

2-Good practice: For the process of identifying personal needs and priority areas, practical instruments that are ICF based, are used during the intake or first assessment.

Two examples of ICF-based instruments (taken from EBU paper on rehabilitation for elderly with sight loss, go to document):

	Medical		
	Functions		
Environment:  Description: Desc	Activities	Participation	Personal:  □ Personal background □ Personal History

'Given an individual's medical condition and functional impairment, the table above identifies, on the one side, physical, social and organisational aspects of the environment which impact on the individual in determining the activities available, and on the other side, the personal background and history that influences the individual's capacity to participate in activities.

This version is easier for professional staff to use in conducting interviews with clients.

The priority is to identify difficulties that present a barrier to daily living and to assess what they can do realistically to overcome these barriers.

A simpler model, the transactional framework, has been modified to reflect the structure of the ICF.

	Objective Concrete factors	Objective Intangible factors	Subjective factors
Societal factors	Impact of physical aspects of the environment	Organisational aspects of the environment	Attitudes adopted by other people and their behaviour
Individual factors	Impact of medically described condition(s)	Background and history of the individual	Present confidence and self-esteem of the individual

The limitation to just six elements makes the framework easy to use intuitively in talking to a person being assessed, to establish the functional impact of impairment and environmental factors that impact on their quality of life. Central to this model as a rehabilitation planning tool is the need to regard the client, not as a passive victim of society but as an active agent negotiating their rehabilitation programme. The model recognises that having an impairment does not prevent an individual from being able to contribute to the benefit of others, it facilitates a process of identifying the individual's particular requirements in terms of support by identifying the barriers they experience in day to day life.

## 3. ASSESSED WITH NINE-PLUS PARAMETERS

#### **STANDARD**

There are many eye conditions that produce many forms of vision distortion. Individuals with partial sight can have very different amounts of vision and ways of seeing that limits their functioning at different levels, and therefore have very diverse needs for support and rehabilitation services that have to be met in a personalised and holistic way.

In order to guarantee access to adequate services that meet individual needs, EBU strongly promotes the standard of using a combined set of NinePlus medical and functional parameters for low vision assessment. This is essential to determine the extent of sight loss, functional vision, and its impact on functional abilities in daily life.

Especially in cases of moderate low vision, practice has shown that visual acuity and visual field alone don't give a realistic picture of the extent to which the functional abilities are affected. Therefore visual acuity or visual field scores should not be the only factors that determine a person's eligibility to access low vision services.

In EBU good practice countries with high level low vision services, the low vision assessment is based on the NinePlus principle, which includes visual acuity and field as only two of the factors to be considered, together with additional functional, personal and

environmental factors, to determine the need for rehabilitation and services.

See below under Tools for the NinePlus parameters.

#### **TOOLS**

If your country does not have any specific low vision rehabilitation and support services in place yet, or if in your country only people with severe low vision and those with blindness can access these, or if strict criteria are only based on visual acuity and visual field to determine eligibility for low vision services, EBU urges you to take action for the promotion and implementation of medical and functional low vision assessment with the NinePlus principle.

#### 1-The EBU NinePlus parameters are:

- Low contrast sensitivity
- Light adaptation and light sensitivity
- Glare sensitivity
- Colour vision
- Night vision
- Fixation
- Visual acuity near and far
- Visual field including hemianopsia, scotomas and floaters
- Magnification needed to read newspaper print

#### PLUS:

- Diplopia
- Horror fusions
- Metamorphosis
- Dominance of the worse eye
- Fatigue
- Reading: low reading vision, low reading speed, many reading errors, reading span, amount of light needed.
- Quality of visual image

The EBU NinePlus parameters are based on the ICF and ICD.

2-Low vision is a condition in which vision cannot be corrected by glasses, contact lenses, surgery or medicine. Having low vision affects one's functioning: daily tasks and activities are difficult. For instance: reading the mail and newspaper, writing, shopping, cooking, watching TV, getting around (orientation and mobility), recognising faces, etc.

3-WHO on disability: 'Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem.'

4-In EBU countries with high level low vision services, low vision is in practice self-defined and anyone who has difficulties due to sight loss can ask for a low vision assessment and receive help.

5-INFO: WHO is in the process of developing standards for low vision rehabilitation, in which EBU is involved and the EBU standards for LV services are being taken into account. Information on the process will be published on the EBU website <a href="https://www.euroblind.org">www.euroblind.org</a>

## 4. WELL-DESIGNED PROGRAMME

#### **STANDARD**

Once the functional low vision and the individual needs and circumstances are assessed, an adequate plan can be designed for one or more priority areas. Main objectives are maximizing independence, quality of life and remaining vision.

Maximizing visual potential must be an option. Partially sighted persons generally wish to use their residual visual capacities, however small, as much and for as long as possible, even when deteriorating further over time. They require visual solutions combined with low vision aids, and additional tactile and/or audio support. Learning new strategies to best use their visual potential, and receiving training in using all necessary optical devices and aids that allow optimum use of the remaining sight is a crucial part of low vision rehabilitation.

Low vision devices should be considered for all ages, from young children to the oldest adults. LVD's are not just for reading, but are also designed to observe the world around us.

Other elements of a low vision support and rehabilitation services plan include support in adapting the home, school and work environments to the new situation with lighting, colours, contrast, etc. Training in daily living skills to plan and undertake activities, including leisure activities, orientation and mobility, self-defense, self-esteem, aids and training to

access information, as well as all emotional, psychological and practical support that people with sight loss, and their families, may need. Include support in education, vocational training and employment when applicable. And the role of peer-support has to be recognized.

The plan, its progress and follow up is always made together with the low vision person receiving the services.

#### **TOOLS**

A well designed service programme has a holistic approach, is resultoriented and has clear, practical goals set for each priority area, identifying the skills, capacities, support, aids and training required, as well as a time-line. It also mentions the rehabilitation specialists involved as well as those from other disciplines. In case of a child for example, this could be a paediatric professional and the school teacher, as well as the parents.

1-<u>UNCRPD</u> article 26.1.a: 'Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths.'

Check also other articles like: 19, 20, 21, 22, 24, 27(e,k).

2-WHO: 'Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.'

#### **ICF-based tools:**

- -The two examples previously mentioned in Standard and Tools 2: <u>ICF-based</u> instruments taken from <u>EBU paper</u> on rehabilitation for elderly with sight loss.
- -Another example: 'To facilitate the use of the ICF in clinical practice, it is essential to have ICF-based tools that could be integrated into the existing processes. In the rehabilitation setting, ICF-based tools can be employed in rehabilitation management the multidisciplinary team can use them to comprehensively describe the functioning of patients experiencing or likely to experience disability, to guide the planning of functioning-oriented rehabilitation services and evaluate changes in the functioning status over a certain time period. Rehabilitation management can be characterized with a problem-solving approach. One such approach based on the ICF is the rehabilitation cycle, called *Rehab-Cycle®*. The Rehab-Cycle® can facilitate the structuring, organization and documentation of the rehabilitation process, as well as help the professionals involved in a patient's rehabilitation with coordinating their actions. This iterative process includes four key elements: 1) assessment, 2) assignment, 3) intervention and 4) evaluation.

# 5. BY A TEAM OF PROPERLY TRAINED, HIGHLY SKILLED PROFESSIONALS

#### **STANDARD**

Adequate low vision services require a multi-disciplinary team of properly trained, highly skilled low vision professionals to support those affected by sight loss

Depending on the personal situation and possible other conditions that an individual with low vision may have, the team can be small or more extensive, multi-disciplinary and inter-disciplinary.

Clear communication and good coordination between the professionals providing services in different areas is key to ensure efficient and effective support and to avoid overlap or voids in the support and rehabilitation programme.

A multi-disciplinary team may consist of: ophthalmologist, optometrist, ophthalmic technician or nurse, social worker, low vision specialist, occupational therapist, psychologist, specialist in mobility and orientation, daily living skills, computer training, and maybe some other specific specialists such as an orthoptist, etc. Interdisciplinary-teams may also include a rheumatologist, a physiotherapist, a geriatric or pediatric specialist, a special support teacher, employment support trainer.

Low vision rehabilitation expert training on a national level is essential to meet a comparable standard level of highly skilled low vision professionals both nationally and in Europe. These can be taught through the existing training curricula or courses, or specially designed training. In excellent low vision services providing countries such comprehensive low vision expert trainings are available as university courses, master programme in low vision or as special course.

#### **TOOLS**

If in your country there are no or insufficient properly trained highly skilled low vision experts due to lack of or insufficient low vision expert training, the following may be useful in your campaigning efforts:

- 1-<u>UNCRPD</u> article 26.2: 'promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.'
- -UNCRPD Article 4.1.i: 'promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.'

2-Good practice example: the initiative by the 3 EBU German-speaking countries Austria, Germany and Switzerland where one and the same low vision rehabilitation specialist training is provided. The training was already widely provided in Switzerland and proved to have good results as it is based on long time practice experience of the developers, Arnd Graf-Beilfuss and Susanne Trefzer of SZB, and involved in the EBU low vision network. You can contact SZB for more information on the material, the training and possible cooperation via <a href="mailto:opt-beratung@szb.ch">opt-beratung@szb.ch</a> and trefzer@szb.ch

Note: More EBU countries may have similar training schemes, but we only obtained full training material and direct input from a low vision expert trainer from SZB.

3-On the internet some on-line low vision tutorials are offered, but experts agree that in order to learn everything about low vision and specific rehabilitation, one needs a teacher, a coach and also the possibility to discuss special cases. Learning by doing could also work, but only with an experienced, highly skilled expert at your side.

4-If no low vision services are available in your country low vision support and rehabilitation could also be set up where eye-care is already available. The same human resources and infrastructure can be used with additional training, equipment and a supply of low vision devices.

This could be a hospital or eye-clinic for example. But it could also be the rehabilitation centres for blind persons. The additional required skills for low vision specialists can be taught through the existing training curricula or courses, or specially designed workshops for in-service candidates.

http://www.cehjournal.org/article/establishing-low-vision-services-atsecondary-level/

#### 6. ON TIME AND ONGOING

#### **STANDARD**

Most commonly, the ophthalmologist refers a patient to low vision services when the need for low vision support arises. This can be either upon indication or request of the patient, or from observation of the ophthalmologist. It is important for a patient to also have the possibility to directly contact low vision service providers for an assessment.

While some people have stable low vision, others may experience further deterioration over time, requiring additional or different low vision rehabilitation and support, adapted to the new situation. This has to be accommodated.

It is clear that rehabilitation reduces the consequences of vision loss and if started at an early stage it is a form of prevention too for the impact of further deterioration. Awareness should be raised of the importance of timely rehabilitation and not to wait for the process of sight loss to advance until a person is badly and unnecessarily disabled by it.

#### **TOOLS**

1-<u>UNCRPD</u> article 26.1.a: '....Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths.'

-UNCRPD Article 25.b: 'Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.'

### 7. IN ACCESSIBLE & EASY-TO-REACH FACILITIES

#### **STANDARD**

Low vision services must be available close to home in easy-to-reach, accessible public or private hospitals and rehabilitation centres, governmental agencies, NGOs, community based services, private specialised optometrists, or in other organizations.

Accessibility is of course not limited to buildings where low vision rehabilitation and support services are provided, and not limited to low vision accessibility. It should be integrated in the general programs and accessibility campaigns, and include the promotion of the design for all principle. However, the specific needs of both bind and partially sighted persons (including those with moderate low vision) must thereby be mentioned.

In most countries with excellent low vision services, rehabilitation and support are provided in hospitals and special rehabilitation centers close to home with the option for longer, temporary rehabilitation away from home in accessible facilities. Also some support services are offered in the home, via telephone and electronically.

#### **TOOLS**

If in your country hospitals, rehabilitation centres are not accessible, easy to reach and close to home, then include these in your campaigning activities, highlighting the specific needs of both blind and partially sighted persons.

- 1-UNCRPD article 25.c: 'Provide these health services as close as possible to people's own communities, including in rural areas.'
  -Article 9 Accessibility 9.1: 'States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

  a. Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- -See also UNCRPD article 25: 'States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.'

b. Information, communications and other services, including electronic

services and emergency services.

2-If your organisation does not have its own checklist: There are many good checklists available on the internet regarding the accessibility of a building and the built environment, including the importance of lighting and contrast for persons with low vision, and other features to meet the needs of both blind and partially sighted persons.

Accessible information before, during and after a visit to the centre should be provided. A clearly marked and safe walking route from the nearest public transport stop to the building should be included. Staff should know the guidelines on how to meet and assist a person with sight loss.

For example, see the NCBI website:

https://www.ncbi.ie/information-for/architects-engineers

https://www.ncbi.ie/information-for/architects-engineers/making-hospital-buildings-accessible

and the Light house International site where you can download these brochures:

http://www.visibilitymetrics.com/sites/visibilitymetrics.com/files/download s/Making Text Legible-Brochure.pdf

http://www.cs.mtu.edu/~nilufer/classes/cs3611/interestingstuff/designing-with-colors-1/color\_contrast.htm

3-Good practice example: Often campaigns are successful in persuading local authorities and bus companies to add a bus-stop on a given route, close to a facility related to health services.

- 4-Good practice examples Walking route:
- -Clients of a rehabilitation centre receive a well-thought walking route that is the easiest and safest, instead of a shorter but more complicated and less safe path.
- -In one of EBU's member countries, the problem of a difficult route to the organisation's rehab centre was overcome by offering a volunteer service to guide the client from the station to the rehab centre, while other organisations offer a volunteer service to guide the person from door to door; from home to the rehab centre and vice-versa.

#### 5-Good practice examples Transport:

In several EBU countries transport services by taxi are available to persons with a (visual) disability whereby the price is the same as that of public transport and most EBU countries have a system whereby one can travel with a guide in public transport, only paying for 1 passenger instead of two. In other countries, the social security health system offers to cover the cost of a taxi for the duration of the treatment, for persons who cannot travel independently by public transport.

## 8. FREE OF CHARGE OR AT LOW COST

#### **STANDARD**

All persons with sight loss in EBU countries can enjoy their right to access adequate rehabilitation and support services if these are provided free of charge or at low cost.

The provision of rehabilitation and support services, both for partially sighted and blind people, should be free of charge or very affordable in all EBU member countries. Financing must be assured independent of donations and charities. Rehabilitation services should therefore be state funded as part of the national health care program.

In EBU countries with good rehabilitation and support services for both blind and partially sighted people, such services are provided through the social security system and health-insurance. Also in the majority of countries that currently only provide services for the blind, the cost is covered by the state, and the same must apply for those with sight loss needing low vision services.

In EBU countries with high level low vision services, the government funds, as part of the rehabilitation and support services, assistive technology and support workers that people with sight loss might need to carry out their activities, including, but not restricted to their studies and jobs.

All countries should strive for a national eye care plan that includes low vision as well as blindness within their national health care system.

#### **TOOLS**

If in your country low vision rehabilitation and support services are not provided by the government, are not state-funded as part of the national health-care and social security system, or are not free or very affordable, or only services for blind persons are free and available, action is needed.

1-<u>UNCRPD</u> article 25.a: 'Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes...' (including health-related rehabilitation)

2-WHO: 'Governments established national programmes and regulations to prevent and control visual impairment; eye care services are increasingly available and progressively integrated into primary and secondary health care systems, with a focus on the provision of services that are high quality, available and affordable.'

#### 9. RAISING AWARENESS

#### **STANDARD**

Not everyone with sight loss knows that low vision support and services are available to them. Some are struggling day to day with bad eyesight for a long time before they find out that solutions like a CCTV or vision training exist.

Sometimes professionals do not refer their patient to low vision services and rehabilitation, because they don't check the functional vision nor ask about the possible problems that a patient with sight loss may have in daily activities. This leaves the patient in a sort of limbo, thinking their reduced sight is part of their condition that they have to accept, or that their bad sight is not bad enough to get help. While at an early stage, simple low vision devices, training, advice and other solutions may make a huge difference in their functioning and improve the quality of life.

It is essential to raise awareness amongst the general public and health care professionals, such as family doctors, on available low vision support and rehabilitation services for persons with different degrees of sight loss, and the importance of early diagnosis and referral to low vision services at the earliest possible stage.

Full and accessible information has to be widely spread. Hospitals, service providers and EBU national organisations are strategic partners in providing information through campaigns and a variety of communication channels in accessible formats.

#### **TOOLS**

Awareness raising explains what low vision is, the different causes, symptoms and risk factors. It explains treatment, and what services, support and rehabilitation is available for someone with vision loss, and it inspires through personal stories by people with low vision. It encourages people to have regular eye-checks too. All this through events, publications, video campaigns, social media and local media.

1-<u>UNCRPD</u> article 4.h: 'To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities.'

2-EBU has a set of simulation photos of different kinds of vision distortion that are available to EBU member organisations that wish to use them. These are available upon request from EBU.

3-EBU is in the process of making a short video about low vision and rehabilitation that can be used by its member organizations. It is expected to be ready by the end of 2016. Other EBU organizations have produced good video material that you may wish to ask permission to use in your campaign (RNIB and the Norwegian NAPB amongst others).

4-Good practice example: low vision rehabilitation centres organise 'open house' days where people can receive information on the services offered.

5-Good practice example: Low Vision Awareness Month!
In USA low vision awareness month is celebrated. A good example to follow in Europe, making it an EBU member countries campaign.

## 10. PREVENTION AND EARLY DETECTION

#### **STANDARD**

Campaigns for prevention and early diagnosis can be sight saving.

In cooperation with hospitals, schools, elderly homes, companies, local authorities and other partners, the EBU national organisation can develop campaigns for regular eye-checks, information on sight loss, avoidable blindness, and support and rehabilitation services for both blind and partially sighted persons. Rehabilitation and support services are also a form of prevention, as WHO and UNCRPD recognise...

#### **TOOLS**

Encourage people to take a complete eye-exam and/or a low vision examination and regular eye checks in order to increase chances of early detection and prevention of unnecessary sight loss.

1-<u>UNCRPD</u> article 25b: 'Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.'

2-Good practice example: in several EBU countries opticians offer the free service of having one's eye pressure taken and if too high, clients are advised to see an ophthalmologist (prevention and early diagnosis of Glaucoma). Opticians in addition have an optometrist visiting once or twice a week, who can advise clients.

3-Another good practice example is the Opto-bus, where people can have their eyes checked and that travels to places like elderly homes and schools. In other countries schools provide the possibility for a yearly check by an ophthalmologist and optometrist who visits the school.

4-Good practice example: the NEI (National Eye Institute, USA) campaign: public and professional education campaign focused on early detection and timely treatment of Glaucoma and Diabetic eye disease and appropriate treatment of Low Vision. <a href="https://nei.nih.gov/nehep/">https://nei.nih.gov/nehep/</a>

### **USEFUL LINKS**

Listed below a small selection of relevant links used in this toolkit. Send additional relevant sites that you recommend to the EBU office so we can include them in the toolbox updates. <a href="mailto:ebu@euroblind.org">ebu@euroblind.org</a>

#### UNCRPD:

http://www.un.org/disabilities/convention/conventionfull.shtml

#### WHO:

- -WHO on rehabilitation: <a href="http://www.who.int/topics/rehabilitation/en/">http://www.who.int/topics/rehabilitation/en/</a>
- -WHO definition of disability: <a href="http://www.who.int/topics/disabilities/en/">http://www.who.int/topics/disabilities/en/</a>
- -WHO factsheet on visual impairment (low vision and blindness): http://www.who.int/entity/mediacentre/factsheets/fs282/en/
- -WHO Factsheet on disability and health: http://www.who.int/mediacentre/factsheets/fs352/en/

#### ICF:

<u>http://www.who.int/classifications/icf/en/</u> (includes Intro and on-line resources)

The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains. As the

functioning and disability of an individual occurs in a context, ICF also includes a list of environmental factors.....

Further examples of ICF-based assessment and rehabilitation tools and how to use them:

#### -Example 1:

http://www.euroblind.org/media/position-papers/EBU-position-paper-rehabilitation-for-elderly.doc

#### -Example 2:

https://www.icf-casestudies.org/en/introduction/introduction-to-icf-based-documentation-tools-and-rehab-cycle

-Example 3: Article on case study: visual impairment, rehabilitation and ICF <a href="http://www.scielo.br/scielo.php?script=sci\_arttext&pid=S0034-72802014000500291">http://www.scielo.br/scielo.php?script=sci\_arttext&pid=S0034-72802014000500291</a>

#### **Community eye health Journal article:**

http://www.cehjournal.org/article/establishing-low-vision-services-atsecondary-level/

#### VISION 2020 report:

www.who.int/blindness/Vision2020\_report.pdf

#### EU

http://eur-lex.europa.eu/legalcontent/EN/TXT/?uri=uriserv:OJ.C\_.2010.083.01.0389.01.ENG

#### IAPB

(Articles 26, 34, 35, 45)

http://www.iapb.org/knowledge/external-resources

#### NCBI

https://www.ncbi.ie/information-for

#### RNIB

http://www.rnib.org.uk

http://www.rnib.org.uk/getinvolved/campaign/socialcare/Pages/socialcare.aspx

Building for Everyone is available from the National Disability Authority.

#### Lighthouse International

Light house International site where you can download these brochures on effective color contrast and on making texts legible:

http://www.visibilitymetrics.com/sites/visibilitymetrics.com/files/download s/Making Text Legible-Brochure.pdf

-http://www.cs.mtu.edu/~nilufer/classes/cs3611/interestingstuff/designing-with-colors-1/color\_contrast.htm

#### ■ EBU: www.euroblind.org

Between October 2014 and February 2015, EBU published three new documents with guidelines for rehabilitation services:

- -Rehabilitation and older people with acquired sight loss
- -Minimum standards for low vision services in Europe
- -Rehabilitation, vocational training and employment

Also check out the following sections for examples and useful resources:

- -EBU working areas: <a href="http://www.euroblind.org/working-areas/">http://www.euroblind.org/working-areas/</a>
- -EBU projects.

#### **TERMINOLOGY**

The 7 most used terms in this EBU toolkit:

**LOW VISION** or Partial Sight: a condition in which vision cannot be fully corrected by glasses, contact lenses, treatment, surgery or medicine. Having low vision means that, despite treatment or glasses, participating in daily activities and performing everyday tasks are found difficult to do. For instance, reading the mail and the newspaper, writing, shopping, cooking, watching TV, recognizing faces, going out and about (orientation and mobility).

**LOW VISION and PARTIAL SIGHT**: two terms for the same condition **VISUALLY IMPAIRED**: the group of blind and partially sighted people together.

**SIGHT LOSS**: different degrees of reduced vision that affects the functioning in daily life activities and tasks.

**UNCRPD**: United Nations Convention on the Rights of Persons with Disabilities

**WHO**: World Health Organization

**ICF**: The International Classification of Functioning, disability and health, is a classification of health and health-related domains. As the functioning and disability of an individual occurs in a context, ICF also includes a list of factors to be taken into account.

47

EBU is the united voice of more than 30 million blind and partially sighted people in geographical Europe. EBU protects their rights and promotes their interests, working towards a more accessible and inclusive society with equal opportunities to full participation in all aspects of social, economic, political and cultural life.

EBU works equally for women and men, young and old, those with additional disabilities and those without. All EBU activities in the different working areas, are guided by the UNCRPD.

With its large network of 44 countries, EBU brings together a wealth of expertise on blindness and partial sight and its implications on the life of millions of Europeans. EBU has become a powerful and recognised voice in the international disability movement.

Founded in 1984, EBU is a non-governmental and non-profit organization registered as charity under French law.

-----

**EBU Office** 

6 rue Gager-Gabillot, 75015 Paris, France

Tel: +33 1 47 05 38 20 | Fax: +33 1 47 05 38 21

E-mail: ebu@euroblind.org | website: www.euroblind.org