Minimum standards for low vision services in Europe

EBU

The voice of blind and partially sighted people in Europe

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UNCRPD Article 26 "Habilitation and rehabilitation" in the UN Convention on the rights of persons with disabilities, reads: "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".

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 have *low vision or partial sight*, two terms for the same condition that we will use throughout this brochure.

Low vision is a condition in which vision cannot be corrected by glasses, contact lenses, surgery or medicine. Having low vision means that, despite treatment or glasses, everyday tasks are found difficult to perform. For instance, reading the mail, writing, shopping, cooking, watching TV, getting around (orientation and mobility).

There are many different causes for sight loss that can affect children and adults of all ages. Diabetes, Glaucoma, cataracts, Retinitis Pigmentosa, Macular Degeneration, Uveitis, Albinism, a tumor, eye-injury, and side-effects of medical treatment are some examples. Irreversible sight loss is also highly age-related and common among people over 65, and women are at higher risk than men. 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 needs for support and services. Their specific needs can only be met adequately in a personalized way.

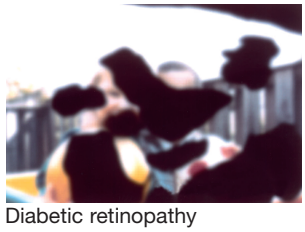
Someone whose sight is deteriorating, needs comprehensive rehabilitation at the earliest possible stage: support, training, aids and services must be available to them free of charge or at low cost and meet their individual needs and circumstances, based on assessment of their low vision with both functional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

Yet low vision support and rehabilitation services differ significantly between EBU member 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 low vision services exist. That means that a huge number of persons with sight loss have no access to adequate low vision services and are excluded from their right to support that enables them to live independently and to participate actively in social, economic, political and cultural life.


Vision with AMD


Cataract


Glaucoma


Diabetic retinopathy

This urgently calls for the adoption and implementation in all 44 EBU countries of binding minimum standards for low vision services in Europe, in compliance with the UNCRPD.

In this brochure EBU recommends a set of ten minimum standards for low vision services in Europe: ten key elements for adequate low vision support and rehabilitation services, based on good practice in EBU countries and on the results of almost two decades of low vision work in EBU to which so many have contributed.


Good vision

MINIMUM STANDARDS FOR LOW VISION SERVICES IN EUROPE

Ten recommendations for adequate low vision rehabilitation and support services:

1. RIGHTS-BASED

All persons with sight loss of all ages and both genders have the right to adequate rehabilitation and support services. Therefore low vision services must be available and accessible to everyone, whether they have moderate to severe low vision, or a condition affecting functional vision.

Good practice: In EBU countries where good low vision services are provided, all residents with sight loss, regardless of nationality, age or gender, have access to and receive low vision services.

2. PERSONALISED

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.

Good practice: For the process of identifying personal needs, practical instruments such as the Activity Inventory (AI) list, are very helpful.

3. ASSESSED WITH NinePlus PARAMETERS

There are many different eye conditions and each one produce a different form of vision distortion. In order to guarantee access to adequate services that meet individual needs, the standard of using a combined set of NinePlus medical and functional parameters for low vision assessment is essential to determine the extent of sight loss and its impact on daily life.

The NinePlus parameters are:

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

PLUS:

- Diplopia
- Horror fusionis
- Metamorphopsia
- Dominance of the worse eye
- Fatigue
- Reading – low reading vision, low reading speed, many reading errors, reading span, amount of light needed.

Good practice: These NinePlus parameters are already common practice in European countries where good to excellent low vision services are provided.

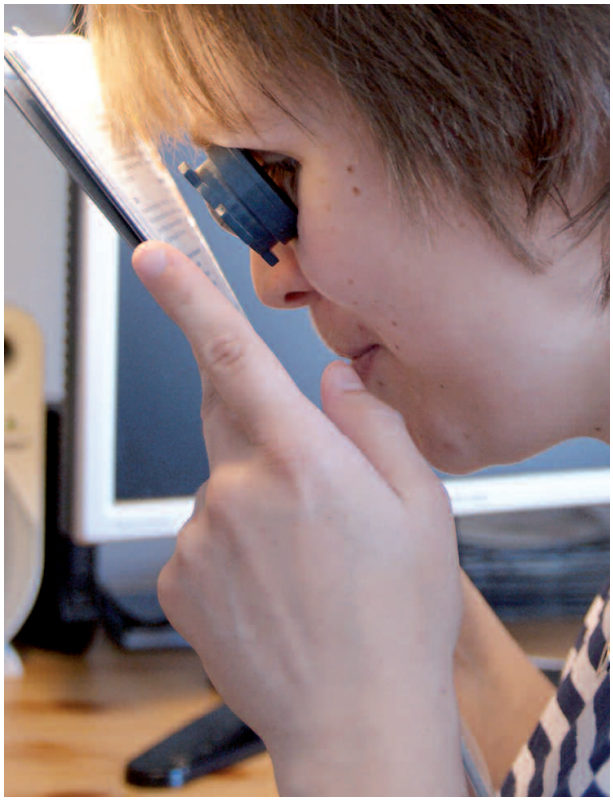
Two real-case examples:
Male, 36 years old, has Stevens Johnson Syndrome and has no tear secretion. The first minutes after moistening his eyes with artificial tears, his visual acuity is 0.40 with a good visual field. Due to the pain caused by cornea erosions he can only open his eyes for a few seconds in dim light. In normal or bright light he cannot open them at all. There was no treatment found. He is admitted to rehabilitation services.

Female, 22 years old, acquired brain injury with a paresis of the right gaze direction. An extreme torticollis. Her visual acuity is 0.60 with a good visual field. In normal head position her visual acuitydrops to <0.05. There was no treatment found. She is accepted for rehabilitation.

4. WELL DESIGNED PROGRAMME

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.

Using 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 in 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 residual sight is a crucial part of low vision rehabilitation.

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-defence, 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.

Good practice: A well designed service programme is result-oriented and has clear, practical goals set for each priority area, identifying the skills, capacities, support, aids and training required.

5. BY A TEAM OF PROPERLY TRAINED PROFESSIONALS

Adequate low vision services include a multi-disciplinary team of properly trained, highly skilled low vision professionals to help those affected by low vision to live as independently as possible and take part in society as they did before the sight loss.

Communication and good coordination between the professionals providing services in different areas is key to ensure efficient support and to avoid overlap or voids in the service programme.

A multidisciplinary team may consist of: ophthalmologist, optometrist, 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, a rheumatologist.

Good practice: In countries with excellent low vision services, professional low vision rehabilitation expert training is available.

6. ON TIME AND ONGOING

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.

7. IN ACCESSIBLE & EASY-TO-REACH FACILITIES

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.

Good practice: In most countries with excellent low vision services, rehabilitation and support are provided in hospitals and special rehabilitation centres close to home with the option for longer, temporary rehabilitation away from home.

8. FREE OF CHARGE or at low cost

All people 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 be state funded. 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.

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

9. RAISING AWARENESS

Not everyone 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.
It is essential to raise awareness amongst the general public and health care professionals, such as family doctors, of available support and rehabilitation services for persons with sight loss. 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.

10. PREVENTION and early detection of sight loss

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.

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

IMPLEMENTATION

Promotion and lobbying for the adoption and implementation of the minimum 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 people of all ages and both genders.

National organisations adhere to EBU´s objectives, principles, and commitment to working equally for blind and partially sighted people of both genders and all ages. Therefore, national 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.

- Take 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 environment;
- Support prevention and early diagnosis programmes
- Promote and lobby for a national eye-care plan that includes both blindness and low vision;
- Cooperate with rehabilitation service providers, monitoring and supporting programmes;
- Participate in national VISION 2020 initiatives;
- Promote the ratification and implementation of the UNCRPD

READ MORE

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

The full text of the UNCRPDarticle 26: http://www.un.org/disabilities/default.asp?id=286

EBU is the united voice of blind and partially sighted people in 44 countries, promoting their interests and protecting their rights.

We work towards an accesible an inclusive society with equal opportunities for all to full participation in all aspects of social, economic, política and cultural life.

EBU is a non-governmental, non-profit making European organisation founded in 1984.

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