

REHABILITATION

for blind and partially sighted people in Europe



3 Position papers



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The voice of blind and partially sighted people in Europe



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3 EBU Position Papers on Rehabilitation

Joint introduction

by
EBU ad hoc working group on rehabilitation

July 2015

To: WHO Europe Director
WHO ICC Europe Chair

Subject: Contribution to WHO new standards for visual
rehabilitation

CONTENTS

Introduction and summary to the three EBU policy papers on Rehabilitation.....	4
Rehabilitation and Older People with Acquired Sight Loss.....	8
Minimum Standards for Low Vision Services in Europe	31
Political Positions Concerning the Labour Market from Self-Help Organisations of Blind and Partially Sighted Persons in Europe	42



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ABOUT EBU

EBU is the united voice of the estimated 30 million persons with sight loss in geographical Europe. The vast majority has low vision, and with the growing population of elderly, the number will only increase in the coming years.

EBU protects the rights and promotes the interests of blind and partially sighted people in 44 countries, contributing to a more accessible and inclusive society with equal opportunities for blind and partially sighted persons to participate fully in all aspects of social, economic, political and cultural life. With its large network, EBU brings together a wealth of expertise and firsthand experience regarding blindness and low vision, and its impact on the daily life of millions of Europeans. All [EBU](#) work is guided by the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

UNCRPD ON REHABILITATION

Article 26, "Habilitation and rehabilitation", of the UNCRPD, says that "State Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to

attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects.

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.'

EBU AND REHABILITATION

One of the working areas in which EBU is active is Rehabilitation and vocational training ([link to EBU working areas](#)).

A survey held by EBU amongst its 44 member organizations in 2014, shows that rehabilitation services differ significantly from country to country – from non-existent through basic to excellent services – meaning that many persons with sight loss are excluded from the rehabilitation and support services they need and have a right to.

This fact calls for urgent action by all stakeholders.

EBU ACTION

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](#)
- [Political Positions Concerning the labour Market from Self-Help Organisations of Blind and Partially Sighted Persons in Europe](#)

In these publications, EBU addresses the exclusion of many persons with sight loss in need of rehabilitation and support services, not only by pointing out causes that risk exclusion but also, and most importantly, proposes guidelines and principles that contribute to improving the current situation.

WHO AND VISION REHABILITATION

WHO (World Health Organisation): '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.

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.’ (quotes from WHO website)

WHO and its partners are currently in the process of developing *Guidelines on health-related rehabilitation*, to provide guidance to governments and other relevant actors on how to develop, expand and improve the quality of rehabilitation services (including assistive technology) in less-resourced settings in line with the *World report on disability* (Chapter 4 “Rehabilitation”). They will also support the implementation of the rehabilitation aspects of the UNCRPD and the *WHO global disability action plan 2014-2021*.

Consultative committees are set up to advise WHO in the process of visual rehabilitation standards. ICC is one of these mechanisms in which EBU is represented, preparing for the WHO IC Conference that will be held in Rome 2015. ICC will: ‘... provide WHO with international standards of care and will define the visual rehabilitation services to be provided at the various levels of the health system in order to make accessible to the patients the basic, upgraded and high level rehabilitation care services.’

EBU as, partner in ICC, brings in the perspective and needs of the users of visual rehabilitation services.

EBU’S PROPOSAL AND RECOMMENDATIONS

Being the united voice of blind and partially sighted people in 44 countries, defending their rights and promoting their interests, EBU highlights the importance of and strongly advocates:

- that standards for vision rehabilitation are rights based, open to all in need of support and services;
- that they are ICF based and not exclusively ICD based;
- that the medical definition is expanded with more parameters than just visual acuity (VA) and visual field (VF);
- that access to services cannot be determined alone by medically-based threshold for visual functioning;
- that therefore the functional definition must be combined with (and may prevail over) the expanded medical definition to assess the needs and to access services that are:

- personalised, meeting individual needs and circumstances;
- taking a holistic and multidisciplinary approach;
- taking into account the specific and different needs of blind and of partially sighted people;
- including physical, functional and psychological support and training (technical aids, skills).;
- provided by properly trained rehabilitation professionals;
- provided in accessible and easy to reach venues;
- accessible financially – paid for by Health system or very affordable;
- including early diagnosis and prevention schemes;
- promoted to the general public and health professionals, raising awareness of the specific needs of blind and partially sighted people and of the specific services available.
- that governments in every country provide:
 - best school and vocational education for blind and partially sighted persons according to article 24 of the UNCRPD. These services ought to be delivered in an inclusive way, but - if necessary - can also be delivered in special schools;
 - sufficient support to enable vocational participation and employment for partially sighted and blind people, so that they may not be dependent on social benefits but earn their own money as a basis for social participation.

MORE INFORMATION

Should you have any queries, wish more information, seek advice, after reading this document and the three EBU publications do not hesitate to contact us at ebu@euroblind.org.

July 10, 2015

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The voice of blind and partially sighted people in Europe

Rehabilitation and Older People with Acquired Sight Loss

Date of issue: 1 November 2014

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GOAL

The European Blind Union (EBU) wants to develop a concrete response to the challenge of ageing of the European population that leads to an increasing prevalence of age-related sight loss. It will be essential that society and governments are aware of the threats to the quality of life of older people with sight loss and of the high costs if these threats are not averted. Therefore governments need to be able to deliver cost effective rehabilitation solutions that: target the specific needs of these older people with visual impairment, support rehabilitation, facilitate less reliance on expensive health and social care support and reduce the need for supported or residential care. In this paper the magnitude of this challenge is supported by figures and specific problems of visually impaired older people are addressed (multimorbidity, psychosocial problems). The role of health care professionals is highlighted (early recognition, prevention, referral) and rehabilitation considerations are suggested that deviate from conventional interventions for younger (adult) people with a visual impairment. Recommendations for service provision are offered, divided into three themes: (1) how should rehabilitation services be offered; (2) what rehabilitation services should be offered; and (3) where should rehabilitation take place. With this paper EBU underlines the necessity for governments and health care professionals to take measures that will increase self-reliance and quality of life of older people with visual impairment. EBU advocates the setting up and maintenance of rehabilitation models specifically aimed at older people with acquired sight loss.

CONTENTS

- Introduction..... 11
- Older People with Acquired Sight Loss – It’s Not Just the Eyes.. 12
 - Impact of vision loss 13
 - Multimorbidity / comorbidity 13
 - Impact of multimorbidity..... 14
 - Consequences for service provision 16
- Rehabilitation..... 17
 - A structured approach to rehabilitation 20
 - Towards a new rehabilitation model 25
 - Application of existing programmes 26
- Recommendations for service provision 27
- Annex 1 29
- Annex 2 30

INTRODUCTION

The term 'visually impaired' is used to indicate blind plus partially sighted people together. Partially sighted and low vision are used as equal indication of limited sight. The abbreviation VIP is often used to refer to a visually impaired person. In this paper we will speak about VIOP when referring to a visually impaired older person and VIOPs in plural. In most European countries 'older' refers to people in the age group of 65 years and older.

The predominant group of people with sight loss is over 70 years of age. Sight loss is often age related and the majority have a condition called Age-related Macular Degeneration, AMD. Within this age group there is a relatively low referral rate. Part of the difficulty is that sight loss in older people is not being recognized as a disability but rather as a part of getting old and that the perception of sight loss often is decided by younger people for younger people.

Europe has a total population of about 850 million people, and it comprises an area covering 15 time zones and 54 countries. Europe has 19 of the world's 20 oldest countries in terms of population age and is predicted to see its populations continue to age to much higher levels over the next 25 years. According to the Population Reference Bureau nearly 25 percent of people in the European Union in 2030 will be above age 65, up from about 17 percent in 2007. As much as 10 percent of Europe's population could be above age 80 by 2050.

Based on global estimates of Resnikov (in *Bulletin of the WHO*, Nov. 2004) it may be estimated that the prevalence of visual impairment (blindness + low vision) in Europe is 1.75% for the total population. About 15 million people in Europe are visually impaired. In the Netherlands 79% of all visually impaired people are 65 years of age or older. If this estimate is also true for the rest of Europe, then there are about 12 million VIOPs in Europe. (Worldwide more than 82% of all VI people are 50 years of age and older). The prevalence of blindness rises sharply in people aged 50+ and increases 3-fold in each decade over 50 years. The prevalence of visual impairment and blindness increases rapidly after about 70 years of age.

In the Netherlands (AMD) ranks as the major cause of blindness and low vision in the elderly and is followed in descending order by glaucoma, cataract and diabetic eye disease. In contrast to the circumstances in Western Europe, cataract ranks as the leading cause of visual impairment among older people in Bulgaria, Armenia

and Turkmenistan, and in the latter two countries uncorrected refractive error represents another one of the four most common causes. Sadly, blindness is often accepted as an inevitable consequence of ageing in these regions. The threat to sight and blindness itself is not a priority and healthcare for older people is often neglected. Experiences, services, funding and attitudes towards VIOPs will be different across Europe. The concept of prevention of visual impairment has yet to be accepted in eye care services throughout eastern regions of Europe (according to dr. Ffytche in Ageing and Ophthalmology). Available statistics (Vision 2020) indicate that prevalence of avoidable blindness generally increases going from west to east. Avoidable blindness is defined as blindness which could be either treated or prevented by known, cost-effective means.

With a loss of vision will often come reduced mobility, reduced access to information, reduced self-regulating capacities, poor confidence to go out alone, resulting in social isolation, reduced physical and mental health, all leading to a downward spiral of dependency.

OLDER PEOPLE WITH ACQUIRED SIGHT LOSS – IT'S NOT JUST THE EYES

As mentioned, the most common age-related eye diseases are (AMD), cataract, diabetic retinopathy and glaucoma. Most of these eye diseases do not lead to total blindness but to low vision, which means that even with regular glasses, contact lenses, medicine, or surgery, people find everyday tasks difficult to do.

Many eye diseases are known to be age-related where the incidence of the disease increases with age, that is, eye disease is more common as people grow older. Ageing is a significant risk factor for eye diseases such as cataract, refractive error and AMD. Age is also a risk factor for diabetes and its vision related complication, diabetic retinopathy.

In their study Kirchberger et al. (2012) found that in a German 65+ population an eye disease is the second most prevalent chronic condition (38.1%). More prevalent is hypertension (57.9%), less prevalent are heart disease (25.8%), diabetes mellitus (16.8%), joint disease (16.2%) and lung disease (10.3%).

Impact of vision loss

Vision loss and blindness are known to have a cumulative negative impact on quality of life of older people. Blindness and vision loss adversely affect the productivity of older people through premature retirement or inability to work and reduced ability to contribute to family life. Older people with good vision are more able to continue their productivity in employment, community and family life.

Ageing and vision loss have a compound impact through:

- Reduced ability to access information and health services.
- Increased risk of depression and anxiety (twice as high as in the non-visually impaired older population) and loss of self-esteem.
- Loss of independence for self-care, daily activities and mobility. Age-related vision impairment has been found to be closely associated with significantly lower everyday competence, as visual capacity is a critical prerequisite for such behaviours.
- Reduced social participation. Some studies show that vision loss does not affect the experience of loneliness dramatically, though others find an increased risk of loneliness.
- Increased risk of falls and domestic accidents.
- VIOPs have shown evidence of diminished well-being. However, the so-called “well-being paradox” in old age (concerning adaptive resources to maintain well-being even under adverse conditions) may also apply to VIOPs.
- Vision impairment is associated with decreased life expectancy among older people, even in high income countries.
- Vision loss at old age leads to a decrease in quality of life and happiness.

Multimorbidity / comorbidity

Multimorbidity is defined as the co-occurrence of two or more chronic medical conditions in one person. Comorbidity refers to the co-occurrence of one or more diseases in relation to a specific index condition, in our case an eye disease. So, on the whole we speak of multimorbidity, but from the viewpoint of an already existing eye condition we speak of comorbidity when it comes to other accompanying diseases.

Multimorbidity is associated with reduced health outcomes including functioning and quality of life, more complex clinical management,

specific health care needs and increased health care costs. The prevalence of multimorbidity is almost 60% in the ageing population.

Co-existence of other health problems is an important barrier to older people accessing eye health care. Co-morbidity of visual impairment and blindness with other illness or physical disabilities works as a barrier in several ways:

- further adds to the difficulty for mobility and the need for assistance to attend eye health care clinics;
- can reduce an older person's strength and physical capacity to undergo surgery or treatment and to self-administer eye-drops or other medications;
- may change the priority of eye health for an individual and loss of vision may not be regarded as important for treatment, compared to other health issues or the effort of having the treatment.

According to Canadian research, vision loss is one of the five types of chronic illnesses that contribute largely to disability in people aged over 65 years, next to foot problems, arthritis, cognitive impairment and heart problems. Other common or important problems are hearing impairment, chronic obstructive pulmonary disease (COPD), falls and hip fracture.

Eye diseases tend to co-occur (in pairs) most often with hypertension, with diabetes, with joint diseases and with lung diseases. One study showed that the high prevalence of comorbidity means that VIOPs over age 80 on average have 4.5 medical diagnoses and 6 prescribed medical drugs per person.

Impact of multimorbidity

Several studies show that among VIOPs on average 75% report having at least one other condition in addition to their eye disease. Different chronic conditions have a different impact on health-related quality of life. Moreover, the combination of certain conditions may cause an additive or synergistic effect. So, in addition to their visual impairment VIOPs may suffer from several other conditions. For example:

- Stroke can lead to weakness, co-ordination problems, locomotor difficulties and problems of communication and continence.
- Coronary heart disease may lead to heart failure, angina or myocardial infarction.

- Diabetes - complications that can contribute to disability in a variety of ways, e.g. the contribution of diabetic neuropathy to poor mobility may be underestimated.
- Alzheimer's disease is the most common neurodegenerative disease. By the age of 85 years, 30% of the population has Alzheimer's disease.
- Urinary problems can be disabling, particularly if causing incontinence.
- Depression is often the result of disability but it also makes disability worse. 10-15% of people aged over 65 years living at home are depressed.
- Visual loss is associated with an increased risk of falling.
- Hearing and visual impairment increase the risk of social isolation and resulting depression.
- Falls are associated with injury, pain and loss of function. The prevalence of osteoporosis in the elderly population means that falls are more likely to result in fractures.

Impaired vision and impaired cognition are independent risk factors for disability in activities of daily living and mobility tasks. Individuals with coexisting visual impairment and cognitive impairment are at high risk of disability, with each condition contributing additively to disability risk. When visual or cognitive impairment is present, efforts to maximize the other function may be beneficial. In general multimorbidity leads to an increased complexity of care systems.

Because of their interdependence the co-existence of vision and hearing loss (dual sensory loss) needs special attention. The overall psychosocial situation of those with dual sensory impairment, which affects about 20% of those 70 years and older, has been found to be worse than for those with single impairments, particularly in everyday functioning. Both sensory impaired groups show poorer subjective health compared with the unimpaired older population.

Consistent with the well-being paradox (Kunzmann et al., 2000; Schilling & Wahl, 2006), the sensory impaired groups show no pronounced differences in well-being-related indicators, demonstrating that older adults, including those with chronic conditions, have considerable psychological resilience for countering functional loss. Nevertheless, those with dual sensory loss report the lowest satisfaction with life, environmental mastery, and positive affect. Together with the health and everyday competence findings, it appears that this group carries the highest psychosocial burden.

Consequences for service provision

There is a relationship between eye disease and having a lower quality of life which emphasises a need for emotional and psychological services for not only the patient but family and caregivers as well. VI individuals are more functionally impaired, they have reduced access to leisure activities, and significantly more co-morbidities as a result of their eye disease. This leads to greater dependence and associated costs. As chronic eye diseases progress, direct non-ophthalmologic costs increase creating the focus on preventing vision loss progression through individualized screening and treatment programs. Vision loss progression from normal vision to blindness increases the odds of depression and other co-morbidities along with greater long-term care utilization, skilled nursing facility admissions, and longer average lengths of stay at acute hospitals which all drive up total costs.

A study in the USA showed that eye-care costs or lack of insurance and perception of 'no need' were the most common reasons for not seeking eye care. Among the older population (> 65 years) the most common reason was no need. A possible reason for this is that older people might regard vision impairment as a normal part of ageing. Regardless of age, men were more likely than women to report no need to seek eye care and women were more likely than men to report cost or lack of insurance as their main reason.

Informal care makes up a large component of indirect costs as patients report utilising more informal, unpaid care from spouses and other family members. This will have strong implications and become a greater burden on future generations. But a problem still exists as the ageing population is rising dramatically yet there are more adults than ever who are single and living alone which may mean less informal care for the visually impaired.

Because ophthalmologists (like other sub-specialties) have limited time per patient they mainly concentrate on the eyes and less on the broader aspects of health. It has been reported that clinicians find it difficult to appreciate the impact of low vision on quality of life. Therefore, it might be helpful for ophthalmologists to understand that low vision and specific coexisting conditions cause a measurable extra burden or even a rapid decline in quality of life. It is recommended that ophthalmologists actively ask visually impaired older patients about their musculoskeletal conditions, COPD/asthma and consequences of stroke, and to continue referring patients with low vision to rehabilitation services. A rehabilitation intervention or a

specific referral to another sub-specialty may be of benefit for the health and vision-related quality of life of the patient and for the involvement of ophthalmologists in their patient's general health.

It is confirmed that loss of everyday functioning is a major characteristic of age-related vision impairment relating to survival. Therefore, investing in maintaining everyday functioning in vision impairment-specific rehabilitation programs seems absolutely crucial. Furthermore it is known that peer support groups have a positive effect on quality of life. For those with dual sensory loss, social communication training and reductions in negative-age stereotyping in the social environment are of great importance.

Knowledge on comorbidity should be an integral part of the education of all kinds of professionals working with visually impaired older people. After all, a multidimensional approach to the understanding of sensory impairment and psychosocial adaptation in old age reveals a complex picture of loss and maintenance.

Integrated provision of services should be a focus so that a timely diagnosis can be reached in order to start timely personalised treatment. Prevention, diagnosis, treatment, rehabilitation, and emotional support should all be services that are integrated into care for VIOPs as prevalence and societal trends will produce a large clinical and economic burden across all levels.

REHABILITATION

The most important aim of this position paper is to enhance participation of ageing people with sight loss. The traditional definition of rehabilitation is insufficient to encompass the complexities of sight loss in older age and therefore a broader, more comprehensive systemic approach is required which is not just about skills training.

Our definition of rehabilitation can be divided into three elements:

- The first is at the level of restoration (recovery of a (visual) function in terms of the International Classification of Functioning, Disability and Health (ICF; WHO, 2001), e.g. neuro-training in increasing visual field in people with hemianopia).
- The second involves skills training which is about learning new skills to compensate for disabilities that result from sight loss, e.g. skills to enable people to use adaptive technology, to get

access to information (incl. ICT-skills), low vision aids, orientation and mobility training. It also includes training or use of techniques for maintaining contacts and a social network towards combatting loneliness and isolation.

- The third element is that of adaptation of the environment - this includes changes in the physical environment (e.g. lighting) as well as the social environment (working with relatives, professionals and care givers). It also includes how the society in which a person lives, contributes to their functioning - transport, financial support, personal assistants, etc - the welfare system.

The challenge for rehabilitation is turning a potential downward spiral into increased independence and engagement in the wider society. This demands an examination of the barriers commonly experienced by VIPs in the light of those aspects of personal characteristics and specific demands of the rehabilitation process outlined by Dodgson (thesis, 2013):

- Resilience - understanding and using this within the rehabilitative programme.
- Information processing - the changes associate with ageing, how this is often assumed to be memory loss and how this can be capitalised on within rehabilitation programmes.
- Learning - the issues related to learning new tasks, e.g. relevance, experience and problem based etc. (Maintaining intellectual stimulation and challenge, using experience, maybe in a voluntary capacity). See annexe 2 for how to adapt rehabilitation services to learning preferences of ageing people with visual impairment.
- Wellbeing - depression - links to sight loss and ageing - Isolation - elderly and sight loss related. (dependence vs. independence; social engagement vs. isolation).
- The ageing process - older people's perception of what old age is and how they can be supported to challenge stereotypes and understand the impact of ageing.

This situation is further challenged by the level and nature of health and social service provision within each European state. Under the current situation in Europe many health services are funded and driven by output targets, often based on isolated factors that don't take into consideration the co-morbidities experienced by many older people who live with diabetes, stroke, arthritis and many other conditions in addition to vision loss which itself often renders people more susceptible to falls and mental health issues such as

depression. The physical environment in which older people live has a major impact on their ability to move about safely, engage in social and leisure activities and on their quality of life. For many people vision loss impacts on social networking opportunities in a negative way and they become more physically and emotionally isolated from others. For some, even the most supportive families find it difficult to understand the complexities of vision loss and its impact, so very often space needs to be created for conversations between the person experiencing vision loss and a professional, and between partners and families before space can be created for rehabilitation that is effective.

Assessment of a persons' functioning therefore needs to be comprehensive and include at least: ocular history, personal care, psychological impact of vision loss, mobility, home management, environment, communication, health factors in addition to vision loss, living situation/support system/service provision and engagement in leisure/social activities.

Priority issues should be identified by the individual and their performance of certain tasks measured alongside their satisfaction with their own performance. The result of this approach is that where a person struggles with a particular task but has no interest in or need to increase their score, resources are not wasted on interventions that are superfluous and are focused on the issues identified by the individual as being most important to them.

Following assessment the level and nature of intervention can be graded along a continuum from one-off, very low level intervention, to ongoing work with a person and their family over a long period of time at a number of different levels, relating to various aspects of their lives.

Rehabilitation covers a multitude of potential activities, interventions and encounters, between people – the outcome of which is intended to be some change in a person's capacity to perform certain tasks, to cope with a particular situation and should open up possibilities for an improved quality of life. In the same way as language continuously seems to evolve in relation to disability (among other things), "rehabilitation" work with people with vision loss, has moved over time. Alongside the evolution of technology and the increasing expectations of people to have full access to both physical environments and information, there has been a change in what people want to be able to do and where they get their sense of fulfilment from. People with disabilities are now recognised as

citizens of the communities in which they live, with rights and responsibilities rather than merely recipients of care, who should be grateful for whatever goodwill is handed to them.

All EU countries have signed the UNCRPD: United Nations Convention on the Rights of Persons with Disabilities. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. It represents a significant change in approach: it treats disability as a human rights issue, rather than only as a social welfare matter. The concept of disability enshrined in the Convention refers to long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder full and effective participation in society on an equal basis with others.

Also VIOPs want to be able to use the latest smart phones, access the internet, connect with family abroad on Skype or email and, even where confidence and capacity to go out and about may be compromised, they want to be part of their chosen network of people, social connections and activities. Rehabilitation has therefore moved beyond, but still includes, traditional models of orientation and mobility and independent living to embrace new opportunities through technology while holding onto the values of peer support, group and one-on-one training and maximising potential.

Rehabilitation outcomes for older people, which they have an input into defining, should be part of any rehabilitation service, and in particular for older people – many of whom, due to changing demographics in Europe and the current causes of most sight loss, are engaging with services for the first time in later life. Models of rehabilitation should be evaluated, reviewed and revised as an integral part of the rehabilitation process and continue to reflect the needs people seeking it and the evolution of the society of which people with impaired vision continue to contribute to as citizens.

A structured approach to rehabilitation

Sight is the most important sense we possess in understanding our environment and any loss of sight has an impact on our quality of life although individuals may be slow to recognise such impact where the sight loss progresses slowly. It may be delayed because of a general acceptance of functional loss across sight, hearing and mobility as a natural accompaniment of age. Awareness may only

become inescapable when an individual meets a situation where their sight is inadequate; something as simple and everyday as reading the newspaper. It gradually presents an increasing impediment to a range of everyday activities as the condition progresses. Reading, driving or using a computer can all be made more difficult or impossible. At a more severe level of sight loss, independent mobility becomes a challenge.

Dealing with these obstacles needs external intervention in the form of equipment and training but the rehabilitation process in relation to older people is made more difficult by frailty and tiredness, lack of confidence, poor motivation and the degenerative nature of sight loss and memory loss; all potential accompaniments to the ageing process. The complex circumstances of progressive disability with age cannot be understood by using the simplistic dualism of medical and social models. They are no longer fit for purpose in an age when we are looking at joined up health and social care. The International Classification of Functioning, Disability and Health (ICF; WHO, 2001) offers a way forward but the complex taxonomy that it provides is difficult to use intuitively and although it is a valuable tool for exchange of information between professionals it is less suitable for informing relatively informal interviews in rehabilitation situations. ICF describes an individual's type and severity of impairment, potential for, and actual level of social activity. It provides a shared terminology and structure that professionals can use to frame their perceptions of a person's condition and how they function in the wider society, with the option of presenting this as a numerical code for the standardised exchange of information between professionals who may operate between different professional frames of reference.

The ICF structure and terminology is complex and would be difficult for a VIOP to follow in discussing their circumstances and possible rehabilitation options. It is not the normal language with which individuals talk about themselves. A more accessible presentation of ICF has been developed at Royal Dutch Visio which identifies the relationship between environmental factors and personal factors in determining an individual's potential for increased engagement in activities and participation.

	Medical		
	Functions		
Environment: <ul style="list-style-type: none"> • Physical • Social • Organisational 	Activities	Participation	Personal: <ul style="list-style-type: none"> • 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. The rehabilitation options, the activities, are part of the individual's environment but it is only the individual who can take responsibility for participation.

This version is easier for professional staff to use in conducting interviews with clients but may still be too complicated for the client to feel full ownership of the rehabilitation planning process. This is a particular problem in face to face work which requires negotiation with the person who needs to understand the basis for any course of action agreed with the professional. The priority in these circumstances 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, which was developed in the 1990's in the UK and used subsequently in staff training in Ireland, 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. The focus for the rehabilitation worker is to assess the individual's capacity, including self-confidence, to deal with these barriers and the type and level of support and training that might be needed to increase this capacity. The transactional framework is complementary to the ICF in providing a relatively simple way of operationalising it.

One of the strengths of the transactional framework is that it explicitly recognises the changes that occur in the relationship between the individual and wider society over the period of an individual's life. The process from total dependence as an infant to being responsible for others as an adult and being involved in complex interdependency as a citizen and employee is a familiar path and we take mutual dependence as the norm, without thinking. Use of medical services for minor injuries, maternity and treatment for hay fever for example, are simply part of the civic environment in some countries; not considered an aspect of mutual dependence. With age, everyone reaches their highest level of functional performance and then falls from this level. Sportsmen become slower and less well co-ordinated, most people have some deterioration of sight and hearing and with increasing age, many people develop arthritis, heart conditions and respiratory problems. The early stages of this process may simply require minimal intervention; new spectacles, a hearing aid or dental treatment. With time, for many, the interventions will become more obtrusive with medication for blood pressure or emphysema, needing recurrent hospital treatment or residential care. This sequence is widely viewed as "natural". This background acceptance of a natural sequence makes it problematical to encourage older people to seek support and treatment to minimise the impact of conditions associated with ageing.

Mobility difficulties may be a consequence of a health condition but a badly designed built environment or inadequate public transport can make the impact of a mobility impairment much greater. The evidence of older people with mobility difficulties living in isolation, perhaps seeing another person only once a week, has been presented over a number of years by EBU members. The link between isolation and depression is well established and it is older people who are most exposed to this risk and, if suffering from depression, are less likely to access support services that may improve their situation. In these circumstances, the local provision of services, including rehabilitation services, is important if they are to be accessible to older people.

The physical environment is not the only barrier that VIOPs face. Across Europe regulations with regard to pensions and benefits vary enormously but appear to have complexity as a common feature so that many older disabled people do not receive their full entitlement. Equally, many older people after a lifetime of working are reluctant to apply for benefits that help to meet the additional cost of impairment because of a current negative attitude towards benefit claimants.

Clearly there are environmental factors, both physical and attitudinal, that have a greater impact on older than on younger people. Nevertheless, not all VIOPs accept these negative consequences of ageing. Adults who have been independent often resist dependence on children or strangers with a resilience developed through their life experience. The attitude of “I can manage” can give individuals the determination to maintain a high level of activity even if they require some rehabilitation, to follow it through. The same attitude can also have the negative effect of making individuals reluctant to recognise their need for some kind of support.

The extent to which an older vision impaired person is active or passive will, to a large extent, depend on underlying personality as well as their past experience. These are factors from their background that cannot be simply removed or ignored. Rehabilitation can only work in the present, to help individuals learn the skills to cope with their current situation. The task is about assessing and increasing the individual's capacity which may need their self-confidence to be enhanced and this is likely to be difficult with older people whose lack of self-confidence may be the result of traumatic loss of sight and sudden dependence on other people. The problem of ageing is that behaviour patterns developed over

decades are difficult to change in a short period. This would imply that programmes of rehabilitation for this group need to be based on long term activities rather than being time limited.

Towards a new rehabilitation model

Although some people access rehabilitation services by making contact and referring themselves, the vast majority of people are referred to rehabilitation services via their ophthalmologist. This means that the relationship between health care professionals and rehabilitation service providers is key to successful outcomes for VIOPs. It is imperative that there is clear understanding of what rehabilitation involves and the difference that it can make to the quality of people's lives, among health professionals and the general public who all have a potential role to play in facilitating older people to access the services that are there for them.

Following referral which may come from a person themselves or a professional, the first step will always be clarification of the request or identification of a person's needs based on their prioritisation of the issues that arise for them as a result of their sight loss. The skills that are required for this first contact are skills in facilitating VIOPs to talk beyond the obvious often more physical issues. Also required is an understanding of how older people present problems or belittle their experience of sight loss in order not to be a burden or "put people out". Knowledge about co-morbid conditions and psychosocial issues is essential for professionals to facilitate this step.

The next step in the model is that the professional reflects back to the VIOP their understanding of what they have heard the person say. Agreement is reached about this and then the professional uses their skills to unpack the needs identified and fine tune the issue – e.g. does the person want to be able to travel to the shop to buy something or find a way to have the shopping done - what is offered in terms of rehabilitation will be different.

The physical environment and social environment will need to be taken into consideration – e.g. are a person's needs best met by engaging with peers in a social setting, attending specialist classes in using adaptive technology or accessing their local gym or community centre through use of a volunteer who may be a younger person or by attending professional counselling services. Within the broad definition of rehabilitation being put forward here, a wide range of engagement by an older person, which may include peers,

volunteers and professionals as well as their own families, is most likely to have the best results in combatting the issues identified by the older person themselves. It also addresses the factors that are widely known to be associated with acquired sight loss in older age – e.g. social isolation, loneliness, low self-esteem and depression.

The needs of VIOPs differ from those in younger age groups in their objectives. There are also differences in learning preferences and learning strategies. All these need to be taken into account for designing the most appropriate rehabilitation context for VIOPs. For this purpose a check list may be used. (See Annex 2).

Application of existing programmes

In addition to the traditional rehabilitation interventions there are examples of good practice in rehabilitation interventions specifically designed to address the rehabilitation needs of VIOPs. There are two already existing and proven programmes initiated by and developed with support of the EBU.

One such example is the INTERGEN programme in which older people and young people learn from each other. Each generation has to deal with its own obstacles, but also has its own know-how. So how can we bring different generations together so that knowledge and experience are shared? Which tools and methodologies are best suited to this venture? The INTERGEN programme is being developed to look at how this can be achieved to link and empower junior and senior people with visual disabilities. Two resource documents from the project are now available in accessible pdf format: the 'Workshop Organisation and Facilitation Manual' and the 'Skills Handbook' both in [English](#), [French](#), [German](#), [Italian](#) and [Turkish](#). For more information check: <http://www.intergenerations.eu/>

Another example is the VISAL project which was based on a friendship enrichment programme, specifically designed for visually impaired older people. British and Dutch experts on visual impairment and ageing have developed a non-formal training course tailor-made to both the age-related and disability-related specific learning needs of VIOPs. The course has been piloted in Austria, Croatia, Slovakia and the UK. Information on the project is available in English, Austrian (German language), Slovakian, Croatian and Dutch. For more information check: <http://www.visal-project.eu/>

Another (national) example is a specifically designed physical exercise programme for older people that originated in the Netherlands (Alma et al., 2013).

RECOMMENDATIONS FOR SERVICE PROVISION

How (1), what (2) and where (3) should rehabilitation services be offered to VIOPs? A logical consequence of what has been said in this paper is that we suggest that VIOPs need to be included in the making of 'their' rehabilitation model and what it means to them, as traditional rehabilitation models are created by younger people for young people. Nevertheless we collected some recommendations related to service provision to VIOPs.

(1) How should rehabilitation services be offered to VIOPs?

- Marketing and awareness in society and amongst professionals working with VIOPs are very important just as the relationship of rehabilitation service providers with ophthalmologists as main referrers.
- Given the prevalence of comorbidity, rehabilitation services for VIOPs should obviously be part of a care chain of service provisions for older people. That care chain includes opticians, general practitioners and practice nurses, ophthalmologists and optometrists, district nurses, carers in nursing homes, mental health professionals and others.
- The needs of partner and family have to be taken into account and they should be involved in the VIOP's rehabilitation programme.
- In rehabilitation services peer support is considered to be highly relevant (see the VISAL example) and is known to a positive effect on quality of life. Support groups are important for this group to help each other e.g. through blind unions and periodic contact through peer support.
- Intergenerational services (see the INTERGEN example) have proven to be useful.
- Use of volunteers and informal care givers will have an added value.
- Tele-rehab (cost-effective) and welfare technology will become more and more important, also for the older generations.
- Staff training and background in working with older people is needed. Knowledge on comorbidity should be an integral part of the education of professionals working with VIOPs. A multidisciplinary approach is necessary considering the

complexity of sensory impairment and of psychosocial adaptation in old age.

- Professionals should be aware of the risk of over-emphasis on formal assessments which may have negative impact on the willingness of older people to accept services.

(2) What rehabilitation services should be offered to VIOPs?

- There needs to be a clear focus on daily practice, with concrete goals based on individual requests/priorities.
- Memory training.
- Physical exercise, to improve strength and balance.
- Low vision assessment and training.
- Use of technology.
- Dealing with loss at old age.

(3) Where should rehabilitation services for VIOPs take place?

- The starting point is that rehabilitation services should be offered on a centre basis, allowing for interdisciplinary working regarding comorbidity and enabling group activity. This is expected to be more cost-effective for the growing numbers of VIOPs, however accessibility, transport and dependency are issues to be taken care of. Different funding regimes in European countries have an important impact on accessibility of rehabilitation.
- Home based follow-up is sometimes necessary. Informal and social contacts are often needed. However, these can be a challenge with regards to funding and how they affect the amount of time each individual receives and from whom.

ANNEX 1

Tables of statistics:

Region	Year	65 years or older	80 years or older
Europe	2000	14.7	3.0
	2015	17.6	4.7
	2030	23.5	6.4

Source: A Tale of Three Cities (EBU, 2013)

Older people in percentages of total population

Year	Eastern Europe		Western Europe	
	≥ age 65	≥ age 80	≥ age 65	≥ age 80
2010	14.4	3.4	18.2	5.2
2020	18.6	4.5	20.9	6.2
2030	22.2	5.8	24.7	7.5
2040	25.6	8.4	28.0	9.3
2050	30.3	9.6	28.6	11.4

Source: A Tale of Three Cities (EBU, 2013)

Prevalence of visual impairment at older ages – French research

	60-69	70-79	80-89	90-99	100+
Low vision	3.06	5.92	14.10	23.13	33.71
Blindness	0.21	0.09	0.91	4.73	3.27
Visual impairment	3.27	6.01	15.01	27.86	36.88

Source: A Tale of Three Cities (EBU, 2013)

ANNEX 2

Checklist to adapt rehabilitation services to ageing people with visual impairment

(Adapted from Andrea Nevins by Peter Verstraten, Royal Dutch Visio - 2014)

- Did you assess your learner's needs to determine the learning objective(s)?
- Does your educational design reflect "need to know" rather than "nice to know" material?
- Have you adapted your materials and approach in addition to the visual impairment to address memory, hearing changes, information processing changes and external factors that influence the older learner's ability to learn?
- Is your design problem-centred rather than subject centred?
- Does your design allow for and expect your learner to take an active role in his/her own learning?
- Have you addressed all three domains of learning (cognitive, affective and practical) as they apply to your topic?
- Does your design employ a variety of educational techniques?
- Are your materials at an adequate reading level?
- Have you made it easier for learners to learn by providing take-home material that summarises your learning points?
- Are all your visuals visible or otherwise accessible for your visually impaired learner?
- Have you considered how to make the learning climate informal, respectful and collaborative?
- Have you considered the need to involve family / informal caregivers in the learning process?
- Have you made learning fun?

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The voice of blind and partially sighted people in Europe

Minimum Standards for Low Vision Services in Europe

By EBU Low Vision network

December 2014

CONTENTS

UNCRPD article 26.....	33
Background	33
Minimum standards for Low Vision services in Europe	35
1. Rights-based	35
2. Personalised.....	35
3. Assessed with nineplus parameters.....	35
4. Well designed programme... ..	37
5. ...By a team of properly trained professionals	37
6. On time and ongoing	38
7. In accessible & easy-to-reach facilities	38
8. Free of charge or at low cost	38
9. Raising awareness	39
10. Prevention and early detection of sight loss.....	39
Implementation	40

UNCRPD ARTICLE 26

UNCRPD Article 26: ‘Habilitation and rehabilitation’ in the UN Convention on the Rights of Persons with Disabilities, reads: “State 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, State 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.

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.

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 both functional parameters and NinePlus medical 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.

Access to services must be based on functional vision assessment, must be person-centred and have a holistic approach – never only based on a strict medical definition threshold.

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 acuity drops 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-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.

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 program.

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 programs
- Promote and lobby for a national eye-care plan that includes both blindness and low vision;
- Cooperate with rehabilitation service providers, monitoring and supporting programs;
- 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/lowvision/>

For the full text of the UNCRPD article 26 go to:
<http://www.un.org/disabilities/default.asp?id=286>

COLOPHON

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The voice of blind and partially sighted people in Europe

Political Positions Concerning the Labour Market from Self-Help Organisations of Blind and Partially Sighted Persons in Europe

EBU Position Paper

February 2015

CONTENTS

1. Vocational Orientation, Vocational Guidance and Vocational Training	44
2. Organisation and Quality of Job Placement	46
3. Work and Employment	47
4. Advanced and Further Training	48
5. Vocational Rehabilitation	49
6. Digital Learning and Working Environment	50
7. Research and Empirical Evidence	50

This paper is based on the UN convention on the rights of persons with disabilities and describes the specific requirements and measures for the implementation of the articles 24-27 with the objective of equal participation of blind and partially sighted persons in vocational training and employment.

The EU, for its part, is required to set the necessary basic conditions to create the prerequisites for the inclusion of blind and partially sighted persons in Europe. The individual Member States need to examine their laws and regulations to the effect that they meet the requirements described in the succeeding parts of this paper. If appropriate arrangements are lacking, they need to be created and the necessary public means need to be provided.

1. VOCATIONAL ORIENTATION, VOCATIONAL GUIDANCE AND VOCATIONAL TRAINING

1.1. Vocational guidance and vocational orientation schemes for blind and partially sighted pupils shall start at the beginning of the third from last year of school attendance at the latest. Their main objective is to systematically prepare the pupils for the choice of career, and this support shall continue until graduation. With the help of a so-called Case Management, guidance and support shall be provided by staff specifically qualified in the field of the respective disability and shall extend beyond the threshold from school education into professional qualification. In order to cover the additional need resulting from the disability, including areas such as diagnostics, the provision of training, assistance or aids, sufficient financial resources need to be provided. Blind and partially sighted persons in education and employment need to be integrated into the process through Peer Counselling. It is imperative to form a solid basis for the decision regarding the choice of career.

1.2. It needs to be ensured that the services of vocational orientation and vocational guidance are oriented towards the potential and wishes of the young persons. In doing so, all kinds of professional qualification need to be considered.

1.3. In accordance with the UN convention on the rights of persons with disabilities, young blind and partially sighted persons have the right to the best possible professional qualification with the objective of participation in employment. Regardless of the form of professional qualification, it needs to be ensured that all needs resulting from the disability can be met at short notice and that thus,

the disability does not cause interferences with the professional qualification or even lead to its discontinuation. The necessary resources need to be provided regardless of the place of professional qualification. The Case Management composed of staff specifically qualified in the field of the respective disability supports the persons through the stage of the professional qualification and also in their transition from the professional qualification into employment. Only in this way the additional burdens and obstacles arising for the persons affected from their blindness or their visual impairment and their social environment can be minimized and entry into working life that corresponds to the suitability and the affinities of young blind and partially sighted persons can be ensured.

1.4. In order to ensure equal opportunities in the labour market, the funding of the additional need caused by the disability needs to be guaranteed for all types of vocational training programmes, from in-firm vocational training or inter-company vocational training through advanced and further training to university programmes, regardless of the income and wealth of blind and partially sighted persons.

1.5. Providers of education schemes explicitly offering their services also for blind and partially sighted persons need to outline how they will achieve this with regard to subject-didactics as well as the provision of accessible instructional material. These conditions need to be stipulated and revised in the context of work experience, as well.

1.6. Analogous to employers of seriously disabled persons, the additional need caused by the disability is funded by the cost unit responsible and not by the provider of the work experience. This means that, unless the services were explicitly agreed upon beforehand, the provider must be able to purchase the necessary equipment at the funding agency's cost.

1.7. We urge the public administration sector to discharge its particular duties to provide education and employment opportunities to blind and partially sighted persons by making specific actions in accordance with the UN convention on the rights of persons with disabilities.

1.8. University studies need to be regarded as a means of professional qualification of blind and partially impaired persons in the context of their programme of education. For this purpose, the following measures need to be taken:

- 1.8.1. The funding of the additional need caused by the disability, including technology and assistance, needs to be guaranteed, regardless of income and wealth, until the highest possible qualification is reached. This includes doctoral studies and possible additional specialisation such as psychotherapeutic training.
- 1.8.2. Meanwhile, work experience abroad has become a common prerequisite of many employment opportunities for university graduates. In order to maintain equal opportunities, seriously disabled persons must not be disadvantaged in this context. Studies abroad, i.e. semesters abroad and postgraduate studies, need to be promoted consistently throughout Europe with regard to the additional need caused by the disability.

2. ORGANISATION AND QUALITY OF JOB PLACEMENT

2.1. Vocational guidance and rehabilitation specialists, as well as the employment specialists within rehabilitation units which are in charge of advising and re-assigning blind and partially sighted persons, need to have qualified knowledge regarding blindness and visual impairment and undergo further training concerning these topics on a regular basis.

2.2. The job placement of blind and partially sighted job-seekers needs to be tailored to the applicants' needs. This means that teams of job agents need to build up and maintain networks of potential employers on the one hand, and need to know the qualification and personality profiles of the applicants affected as well as possible on the other hand. Through the concept of empowerment, the persons affected shall be encouraged to act independently and trained for that purpose.

2.3. The budgets for job placement and rehabilitation, i.e. for employment subsidies and assistive technology at the workplace, need to be in the hands of these teams of job agents so that they are able to negotiate on an equal footing with potential employers of blind and partially sighted applicants. The budgets need to be protected so that there is no competition with the objectives of other types of support that can be delivered more easily, by the job placement centres.

2.4. Unemployed blind and partially sighted employees need to be informed about job vacancies and the means and regulations of support and should not have to negotiate with the job placement centre to get access to this information. They need to be informed directly and all embracing.

2.5. Generally speaking, organisational structures and budgets, and targets need to be adjusted so that seriously disabled persons bear no higher risk of unemployment than non-disabled persons.

3. WORK AND EMPLOYMENT

3.1. The period of time for equipping the workplace of a seriously disabled person with the necessary technology and, if required, with the necessary assistance needs to be as short as possible. The guideline should be: As long as the necessary infrastructure to meet needs caused by the disability is not in function at the workplace, no cost for the employment of seriously disabled staff will arise to the employer but to the job placement center.

3.2. In all Member States, structures to ensure accompanying assistance at work need to be developed. Among other things, these structures ensure that if technical aids fail, a replacement will be provided within one working day. Furthermore, it needs to be ensured that the technical equipment at the workplace which is provided to compensate for disability is always up to date.

3.3. If a blind or partially sighted employee is unable to fully meet the requirements of a workplace in the long term, the employer needs to be granted a permanent compensation for the disability-related difficulties and this so-called „diminished capacity compensation“ needs to be assessed from time to time,. In doing so, equal chances of competition shall be guaranteed in order to secure employment of persons with disabilities in the general labour market.

3.4. If, despite exhausting all means, employment in the general labour market cannot be guaranteed, the blind and partially sighted persons need to be given the possibility to implement their participation in employment through supported employment, social enterprise or a sheltered workshop.

3.5. Incentives to the integration of seriously disabled persons into the labour market need to be further developed in a way that supply of labour will also be possible.

3.6. Opportunities for self-employment for blind and partially sighted persons need to be promoted and supported, similar to the promotion of other employment opportunities.

3.7. Students, highly qualified employees and self-employed persons who are blind or partially sighted depend a lot on accessible international travel. For this reason, the free transport of an accompanying person in means of public transport needs to be harmonised throughout Europe.

3.8. Political schemes concerning the labour market need to be implemented in such a way that the chances of employment of gainfully employed non-disabled persons and those of gainfully employed persons with disabilities do not differ from each other. Likewise, financial means need to be used so that the employment rates and the unemployment rates of persons with disabilities do not differ from the general employment rate and the general unemployment rate. Persons severely affected by disabilities need to be identifiable in statistics and to be supported.

4. ADVANCED AND FURTHER TRAINING

4.1. Opportunities for advanced and further training of all types, ranging from professional adult education courses through further training in the form of educational leave to specialisation, whether they are obligatory, for instance in the case of doctors, pedagogues, etc. or voluntary, need to be fully accessible to blind and partially sighted persons. This requires the consideration of subject-**didactic** requirements on the one hand and the compensation of the additional needs caused by the disability on the other hand. If inclusive participation in advanced and further training offers cannot be realized, the persons affected need to be given the possibility to complete them in special facilities.

4.2. Blind and partially sighted persons also need to have the possibility to gain experience via informal working conditions which may lead to an improved integration into the general labour market, ranging from voluntary traineeships through community work to short-time employment. Material and personal aids need to be financed for this purpose. For logical reasons, pools of assistive

technology, respectively, need to be introduced at the cost units or at third parties that have been commissioned by the cost units. Furthermore, qualified assistants need to be provided.

5. VOCATIONAL REHABILITATION

5.1. All EU citizens experiencing permanent sight loss due to an accident or a disease need to be entitled to have a follow-up treatment, subsequent to the acute treatment. In the course of the follow-up treatment, basic concepts such as mobility skills, independent living skills, and the use of assistive technology should be taught (first step of an adjustment to blindness training). In the course of this scheme, the process of the vocational and social rehabilitation of patients of working age needs to be supported through in-depth counselling and assistance when applying for the required services.

5.2. Every blind or partially sighted person of working age needs to be entitled to adjustment to blindness training. Its funding must not be solely subject to economic considerations of the cost unit responsible.

5.3. University studies need to be recognised as an opportunity for vocational rehabilitation of seriously disabled persons. To give an example, persons who lose their sight later in life currently have no possibility of getting financial means for the additional need caused by disability in order to complete university studies.

5.4. The guideline for vocational rehabilitation schemes should be: Preferably tailored to the individual, preferably offered by qualified staff, preferably close to the place of employment, preferably close to the place of residence. If no suitable company or unit that can provide the necessary support is available at the place of residence or in the surrounding area, the persons affected need to have the option for a vocational rehabilitation scheme in a special centre for blind and partially sighted persons. The objective needs to be a timely and sustainable re-integration into the primary labour market.

5.5. In order to secure a sustainable performance, vocational rehabilitation centres for blind and partially sighted persons need to receive sufficient financial means for being able to meet the respective needs.

6. DIGITAL LEARNING AND WORKING ENVIRONMENT

6.1. Accessible and usable computer programmes in school, education and employment are an essential basis for the inclusion of blind and partially sighted persons. It needs to be ensured that at schools and universities as well as in companies and public institutions only accessible and usable software is implemented, to enable the persons affected to work with screen-readers and keyboard commands without using the mouse.

6.2. Not only in schools of general education but also in vocational schools the learning platforms or electronic classrooms and the learning software provided needs to be examined with regard to accessibility and usability and it has to be adapted, if it fails. Blind and partially sighted pupils and students must be able to use it on an equal basis with others. If this prerequisite has not been fulfilled, an assistant needs to be provided. However, s/he can only be of temporary help. In the future, only programmes that are evidently accessible and usable may be purchased.

6.3. Accessible and usable computer programmes at the workplace are a vital prerequisite for the economic employment of blind and partially sighted persons. The requirement of accessible and usable websites of public entities needs to be extended in a way that all applications of public employers are tested with regard to usability and adapted, as necessary. In the future, only software that is evidently usable may be purchased. If employment of a blind or partially sighted person is in danger of failing due to inaccessible software, assistance needs to be provided until usability has been achieved.

7. RESEARCH AND EMPIRICAL EVIDENCE

7.1. A statistical reporting system providing information about the employment and unemployment of (seriously) disabled persons is essential. Information should be provided about the type and degree of the disability as well as further relevant aspects. It needs to be developed in such a way that it can form the basis of an adequate employment policy.

7.2. The working environment is subject to permanent change. For that reason, the opportunities of employment for blind and partially sighted persons as well as for persons with other disabilities need to

be extended and enhanced. In order to achieve this, specific research programmes need to be applied, particularly with regard to the analysis of new occupations and business areas, for the analysis of new vocational fields and for further development of existing occupational profiles. Research projects concentrating on the group of low-qualified blind and partially sighted persons and on the analysis of new fields of activity in the primary labour market are of particular importance.

7.3. The qualification of experts to work in schools, vocational education and the rehabilitation of blind and partially sighted persons in Europe needs to be ensured and developed further. The centres for further and academic training for teachers of blind and partially sighted pupils as well as for rehabilitation specialists need to be secured and equipped with professionally and scientifically trained staff.

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