EBU Policy Statement on Low Vision

EBU Commission on the Activities of Partially Sighted People

EBU Commission on Human and Social Rights

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1. INTRODUCTION

In this document a policy statement is proposed for adoption by the European Blind Union. The statement constitutes a guideline for the advocacy of the interests of partially sighted people. ‘Who are they?’ has been, from the beginning, the central question in a lively, sometimes fierce, debate in our Commission. For outsiders it was not always easy to understand the discussion as the terminology changed during the last fifteen years. In the past, the term ‘visually impaired’ was reserved for those people we now call ‘partially sighted’. At present ‘visually impaired’ means ‘blind and partially sighted’. Even the word ‘handicap’ has another meaning since the publication of the official first definition in 1980 by the World Health Organization (WHO). Fifteen years ago we, partially sighted people, would have described ourselves according to the ‘medical model’ of the WHO (1) as visually handicapped
because we were not able to participate in society in the same way as normally sighted people. Today, we should not be called handicapped with a visual impairment if low vision aids and an accessible environment enable us to participate in society (2). And, to make the discussion even more difficult to understand, two different concepts are used to denote the same concept: 'low-vision' and 'partial-sight'.

Important statements in this document are about definitions: 'legal', 'medical' and 'functional' definitions. Even the term 'functional definition' now has a different meaning from that which it had fifteen years ago. Therefore, before presenting and clarifying the statements, we offer you a historical review to facilitate a better understanding of the policy statement.

2. THE DISCUSSION ON DEFINITIONS WITHIN THE EBU COMMISSION ON ACTIVITIES OF PARTIALLY SIGHTED PEOPLE

2.1 The discussion during the period 1986 - 1996

The EBU, the European Blind Union, represents the interests of blind and partially sighted people. However, it has not always been that way. Since the 'Low Vision Conference' in Lunteren in the Netherlands in 1986, the EBU has been aware of the increasing number of partially sighted people caused by the aging of the population and, at the same time, the decreasing number of blind people caused by the improved medical care. In the opening speech the first chairman of the Commission on Activities of Partially Sighted People, Theo Walraven, clearly formulated the problems and needs of partially sighted people and how these needs differ from the needs of blind people. Since its Second General Assembly (Varna 1987) the EBU has had a Commission that paid special attention to the problems of partially sighted people. This Commission started as a Sub-Commission of the Commission on Rehabilitation. At the Third General Assembly (Lisbon 1990) it was given the status of a Standing Commission.

One of its primary tasks was to formulate a legal definition of partial sight, and promote its adoption throughout Europe. Finding a satisfactory definition proved to be a difficult job. Today in most industrialized countries, visual acuity, while a global indicator, should not be used as the sole or main criteria for access to services. The functional vision and its impact on normal living skills and tasks is a better measure (2). This will become more significant as the population ages. Significant vision loss with aging makes other challenges that are much more acute and handicapping. As a result, someone who has an certain visual acuity just above the 'magic' number may be more limited than someone with a lower visual acuity but with greater health and/or well being.

The Commission tried to tackle this problem in three steps. The first step was to approach the problem of defining partial sight from a 'functional' point of view. At the Fourth General Assembly a list of nine visual parameters was presented and adopted that are relevant for an improved assessment of partial sight in individuals. These nine parameters were: light adaptation, colour vision, fixation, glare sensitivity, low contrast sensitivity, magnification needed to read newspaper print,
night vision, visual acuity and visual field. These parameters were combined in a questionnaire that was later presented at the Fifth General Assembly, with the intention to introduce it in all European countries. Moreover, this questionnaire was also introduced by Fritz Buser (3) at the International Conference on Low Vision, ‘Vision 1993’ in Groningen in the Netherlands. With this questionnaire it is possible to get a more accurate assessment of the visual functions than is possible on the basis of visual acuity and field of view alone.

The second step in tackling the problem of defining partial sight was to formulate principles on the accessibility of provisions for partially sighted people. These principles, presented and adopted at the Fourth General Assembly, referred to all kinds of rights and services provided by the government, by public institutions or by organizations of blind and partially sighted people. They also included recommendations on how to formulate membership criteria for organizations of blind and partially sighted people.

The follow-up activity, the third and final step, was to organize a conference to prepare a ‘programme of action’ to meet the needs and aspirations of people with partial sight. Crucial in this program was to decide who is included as a partially sighted person and who is not. So the conclusive action was to assign threshold values and weightings for the nine parameters of the visual functioning questionnaire to create criteria for inclusion. The conference, which was to be attended by partially sighted people, their organizations, those providing services and advice plus representatives from local and national governments would be an ideal platform to discuss this matter.

The conference was planned to be held in Poland in 1994. Regrettably, only a few members of EBU organizations registered for the conference. The conference had to be cancelled, thereby interrupting the process of developing a legal definition of partial sight on the basis of functional visual parameters. This was especially disappointing as another organization, the International Society for Low Vision Research and Rehabilitation (ISLRR) appeared to be able to organize well attended conferences on low vision in the same period: 1993 in Groningen and 1996 in Madrid.

2.2 The discussion during the period 1996-1999

In the next period, when Berry den Brinker was chairman, it continued to be a primary duty for the Commission to seek a legal definition of partial sight, and its adoption by governments throughout Europe. Commission discussions have however, taken another direction. It was concluded that the organizations for blind and partially sighted people should work for ‘A Society for All’, a concept that was directly copied from the Swedish Organization of Visually Impaired People. In ‘A Society for All’ blind and partially sighted people should all be able to take part in society as equals with other people. Therefore, The Commission concluded, it was not very important to make sharp distinctions between blind, partially sighted and normally sighted people as all people having a visual impairment had to be supported in their efforts to take part in society.
2.3 The discussion during the period 1999-2003

In the present mandate period, since Giuseppe Castronovo became chairman, the EBU Board again proposed in its first meeting in Antwerp to establish a legal definition of partial sight. The members of the Commission expressed their preference to work on a functional definition. The members of the Commission were well aware that it no longer makes sense to exclude people from services or membership on the basis of medical criteria (visual acuity and field of view) that have proven in scientific research to have only an indirect relationship with the problems encountered by low vision people in their daily life (4). It was also clear from scientific research that it would not help either to introduce some extra visual parameters to define partial sight in addition to the visual parameters that have been proposed by the Commission in the Third and Fourth General Assemblies. Moreover, according to a large epidemiological study conducted in the Netherlands and the UK, two third of elderly visually impaired people and one quarter of younger visually impaired persons suffer from additional disabilities (5,6). So the impact of a visual impairment is very much dependent on other individual factors that cannot be taken into account in a medical definition of partial sight. It would be unjustified to exclude people from services solely on the basis of a visual criterion, as the impact on daily life activities depends very much on non-visual parameters. Today, under the influence of the disability movement, a functional definition refers directly to the ability to live independently and take part in society. So it was decided at the meeting in Antwerp to strive for a functional definition of low vision.

Another important topic discussed in Antwerp was the availability and efficiency of low vision services. Low vision services are centred on the delivery of low vision aids and training programmes; how to use these aids in order to cope with disabling situations. Many new technologies have been developed to help partially sighted people to live independently. However, the world is changing and increasingly becoming a man-made world. Many new technologies have changed life for normally sighted people and new barriers are being created for partially sighted people. Today, computers are difficult to handle and cash payment systems such as ATM's are completely inaccessible for partially sighted people. It is no longer merely sufficient to support low vision people on an individual basis to cope with their disabilities. The public environment needs to become and remain accessible for them, with and without the use of low vision aids. This approach is similar to the action undertaken by the disability movement to ensure the accessibility of the public environment for wheelchair users. So it was also decided to work on this theme in Antwerp.

This resulted in the preparation of a paper entitled 'A society for all, including partially sighted people' which has been adopted by the EBU Board and published on the internet (7). The articles of the Policy Statement below are primarily derived from this publication.

3. DEFINITIONS, FUNDAMENTAL RIGHTS AND POLICY STATEMENTS
3.1 Introduction

The Policy Statement on Low vision offers a firm guideline for thinking about and advocating the interests of partially sighted people. The ideas developed earlier in the paper 'A Society for All, including Partially Sighted People' (7) are in line with the new philosophy of the World Health Organization regarding the consequences of impairments and disabilities. What was started by the WHO in 1980 as the 'International Classification of Impairment, Disability and Handicap' has become, under the influence of the disability movement, an 'International Classification of Functioning and Health' (ICF). The WHO makes the following remarks about the development in thinking about the genesis of disability (2).

Start citation:
"A variety of conceptual 'models' have been proposed to understand and explain disability and functioning and handicap. These may be expressed in two opposing views of the 'medical model' versus the 'social model'.

The medical model views disability as a problem of a person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at cure or the individual's adjustment and behaviour change. Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy.

The social model of disability, on the other hand, sees the issue mainly as a socially created problem, and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary, or the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. For this model disability is a political issue.

ICF is based on an integration of these two opposing models. In order to capture the integration of the various perspectives of functioning, a 'biopsychosocial' approach is used. Thus, ICF attempts to achieve a synthesis, in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective".

End citation.

The ICF offers tools to 'measure' the health condition of individuals and the environment they live in. Consequently, it is now possible to measure the 'quality of life' and to have indications for measures to improve it. These measures may be 'medical' or 'social' in nature or a combination of both. The guiding principle in selecting between these measures, we firmly believe, has to be to maximize equal opportunity for full participation in society. This holds for each individual partially sighted person and for all partially sighted people as a group. The definitions and fundamental rights as formulated below, form the basis for the EBU policy to attain
full participation for all partially sighted people.

3.2 Definitions

- **Article 1: Medical definition of low vision**

  The EBU affirms the following as the official medical definition of Low Vision as evolved by the World Health Organisation (WHO):

  "A person with Low Vision, also called a person with partial sight, is one who has impairment of visual function, even after treatment, and/or standard refractive correction and has an acuity of less than 6/18 to light perception, or a visual field of less than 10 degrees from the point of fixation, but who uses or is able to use, vision for the planning or execution of a task." (WHO Bangkok, 1992).

  The number of visually impaired people is estimated by the WHO to be 180 million (3% of the population) of which 135 million are partially sighted. In western European countries the number of visually impaired people is estimated to be about 2% of the population of which 90% is partially sighted.

- **Article 2: How to use the medical definition to advocate the rights of partially sighted people?**

  The medical definition of partial sight is a useful tool for estimating the number of people in a given area suffering from one or more forms of visual impairment. This facilitates planning for the development and resourcing of present and future services. However, this application should not be considered to be any more than a guideline and should not be used as a criterion for inclusion of individual persons in services.

- **Article 3: The scope of the medical definition of low vision**

  The EBU is conscious of a relationship between visual impairment and disability. However the EBU rejects a complete causal relationship between visual impairment and disability, as propagated for many years in 'medical models'. The EBU is aware of the absence of a 'one to one' relationship between visual acuity and field of view on the one hand and appropriate services and low vision equipment on the other. Services should be based on the evaluation of the personal needs and not exclusively on medical diagnostic values. In other words, it is not the visual acuity and/or a restricted viewing field, but the need to get support to do essential activities that determine the access to (medical) services.

- **Article 4: Functional definition of Low Vision**

  A partially sighted person is defined as a person for whom the reduced vision affects one or several of the following activities:

  - Reading and writing
  - Orientation and mobility
  - Activities of daily life
  - Communication
  - Maintenance of any visual task
• Article 5 : The definition of disability

The EBU supports the definition of disability as advocated by the international disability movement:

'A Disabled Person is an individual in his or her own right, placed in a disabling situation, brought about by environmental, economic and social barriers so that the person, because of his or her impairment(s), cannot overcome the imposed barriers in the same way as other persons. These barriers are all too often reinforced by the marginalizing attitudes of society towards people with impairments. It is up to society to eliminate, reduce or compensate for these barriers in order to allow each individual to enjoy full citizenship, respecting the rights and duties of each individual'.

• Article 6 : Definition of membership of organizations of visually impaired people

Everyone suffering incomplete participation in society as a result of a visual impairment should belong to the interest group of the members of the EBU. The medical definition of partial sight may not be used to exclude visually impaired persons from medical and low vision services.

3.3 Fundamental rights of partially sighted people

• Article 7 : Right to use (enhanced) vision

Partially sighted people use a combination of vision, vision enhancement and vision substitution techniques to cope with their visual impairment. Partially sighted people have the right to make optimal use of this sight. In order to do so, partially sighted people have the right to have at their disposal all appropriate low vision aids and equipment, services, and a visually adapted environment.

• Article 8 : Fundamental rights of all groups of partially sighted people in society

In addition to Article 7, the EBU stresses that all partially sighted people should have access to low vision aids and services. This is particularly important for elderly people and women and men not having access to low vision services because they are not engaged in an education program or a regular job.

• Article 9 : Fundamental rights to personal assistance

Even when partially sighted people receive low vision aids, low vision training and their personal environment is adapted to meet their needs, there may exist essential tasks that cannot be undertaken. As a consequence, partially sighted people are substantially disadvantaged in these situations and are unable to make the best use of their potential abilities. The provision of personal assistance would enable partially sighted people in these situations to develop their potential abilities, and thereby lead more inclusive life in their communities and society. Partially sighted people have a right to the provision of funded personal assistance to undertake essential tasks.

• Article 10 : The Right to medical treatment
Some eye conditions are amenable to treatment, especially if this is timely. At present many people become partially sighted because treatment is not available, or it is not provided when it can be most beneficial. People with eye conditions that are amenable to treatment have a right to receive such treatment.

- **Article 11 : The right of a barrier free society**

  Partially sighted people have the right to a barrier free society, including visual access to public transport, public buildings, participating in public leisure and social activities, using information services and banking facilities.

- **Article 12 : The right to a barrier free society using low vision aids**

  Partially sighted people have the right to be enabled to use their low vision aids to overcome barriers while travelling, visiting public buildings, participating in public social activities, using information systems, banking systems, etc. Solutions for partially sighted people in the context of 'Inclusive Design' are in general visual in nature in contrast to the solutions for blind people.

### 3.4 Policy statements

- **Article 13 : Anti discrimination legislation**

  The EBU sees the disadvantages that many disabled visually impaired people experience, as a form of injustice, which requires a legal and political response in the form of anti discrimination and human rights legislation.

- **Article 14 : Political action for collective and individual protection**

  In protecting the interests of partially sighted people the EBU classifies its political actions in two categories:

  1. Actions against disabling situations in society caused by imposed barriers. These actions should result in legislation that leads to collective measures such as the obligation to apply universal design principles for access to the public environment and information systems.

  2. Actions to promote the introduction and implementation of legislation that guarantees individual services for partially sighted people, e.g. prevention, medical care, rehabilitation, low vision aids, low vision equipment, personal assistance and financial support.

- **Article 15 : Public awareness**

  In order to promote the implementation of Article 14, the EBU gives high priority to actions to raise public awareness of the difficult situation of partially sighted people.

- **Article 16 : Separation of visual and non-visual needs**

  Solutions for partially sighted people in the context of 'Universal Design' are in general visual in nature in contrast to the solutions for blind people that are based on auditory and tactile methods. The solutions for blind and partially sighted people
should be seen as two different approaches. Both approaches have to be utilised when applying universal design principles to meet the needs of disabled and non-disabled people.

Berry den Brinker
Amsterdam, January 24, 2003