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Vision for Vision

Project

„Vision for Vision“

REPORT ON THE SITUATION OF VISUAL HEALTH IN BULGARIA

SUMMARY

January, 2020

Bulgaria is among the countries whose unmet eye and visual health needs are, on average, more than 4 times higher than those in high income countries, with the needs among the vulnerable population groups exceeding that number many times over. There is no established mechanism for coordination at central and local administrative levels between the health, social and education sectors, intended to provide measures for limiting blindness and guaranteeing the rights of those affected.

Currently, there are approximately 2.2 billion people in the world living with impaired vision or blindness; with over 1 billion of them, this condition could have been prevented or still needs care. According to the World Report on Vision of the World Health Organization (WHO) published in October 2019, the leading causes of the growing number of visually impaired people are the aging populations, lifestyles, limited access to eye care, particularly in the low and middle-income countries. The severity of the eye diseases and impaired vision is unevenly distributed; it is significantly higher among the population in the disadvantaged geographical regions, among low-income people, women, the aging population, people with disabilities, ethnic minorities. The people with severe visual impairments cannot participate in social life and reach their full potential due to lack of access to rehabilitation care.

RETINA BULGARIA

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BLINDRAFÉLAGIÐ
Samtök blindra og sjónskertra á Íslandi
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In the coming decades, if the projected increase in the aging population is not met with growth in improving access to eye care, there will be a significant increase in the number of people with visual impairments and blindness.

With its World Report on Vision, the WHO seeks to encourage the countries to take the necessary national action to address the challenges listed, offering integrated eye health focused on the individual. Integrated care means eye health based on interconnected health promotion, prevention, treatment and rehabilitation measures across the spectrum of eye diseases. Integrated care means that these measures are coordinated, both across the health sectors and outside health care, in accordance with the needs of the individual throughout his or her life. Integrated care should contribute to the achievement of universal health coverage and towards meeting Sustainable Development Goal 3: to ensure health and well-being for everyone at any age.

The WHO concludes that the challenges to the health care systems are substantially increasing and expanding, and that the need for data collection for planning purposes is critical to meeting the increasing needs in ocular and visual health.

Led by the desire to raise civic awareness and that of central and local authorities about the number and problems of people with visual impairments in our country, the Vision for Vision project team produced a report on the state of visual health in Bulgaria, based on parts of the WHO report as a first step towards meeting its project objectives.

With this report, the team has sought to summarize the available statistics on the current number of blind and visually impaired people in the country; to highlight the main and specific (for Bulgaria) causes for visual impairment and blindness,

To identify the major gaps and inconsistencies in the existing regulations and policies, in the existing

Medical, social and educational practices and standards relating to visual health in Bulgaria.

The purpose of the analysis is to serve as a starting point for an informed debate with experts in eye and visual health, with visually impaired persons, and with responsible institutions. Based on the findings of this debate, the team is committed to preparing recommendations, at a later stage in the implementation of the project, for strategic guidelines for eye and visual health care in Bulgaria containing the necessary measures to deal with visual impairments and blindness.

The report, published in January 2020, is intended for an audience consisting of representatives of different stakeholders: healthcare professionals, patients, authorities, industry. The team which has drafted the report welcomes any proposal for supplementing it with information that can contribute to its updating and completeness with regard to the project objectives.

1. Vision, eye diseases, visual impairments

Vision - the most dominant of our senses - has an important role in all aspects and stages of our lives. We take eyesight for granted, but without it we are prevented from learning how to walk, getting education, and working. A visual impairment occurs when an eye disease affects the visual system or one or more of its functions. A visual impairment has significant consequences for the course of human life. However, many of these effects can be mitigated through timely access to quality eye care or rehabilitation.

Eye diseases that can cause visual impairment or blindness, such as globally are cataracts, trachoma and refractive abnormalities, are a major focus of prevention and the rest of eye health strategies. At the same time, the importance of eye diseases not typically causing visual impairments, such as conjunctivitis, dry eye etc., which are often among the leading causes of seeking eye care in all countries of the world, should not be overlooked.

The main reasons that can lead to visual impairment in order of importance are as follows:

- Refractive anomalies - myopia, hyperopia, astigmatism, presbyopia
- Cataract
- Glaucoma
- Age-related macular degeneration
- Violation of the transparency of the cornea
- Diabetic retinopathy
- Trachoma
- Rare eye diseases
- Injury

2. Importance. Eye diseases and visual impairments

2.1. Prevalence rate

Eye diseases have a remarkable prevalence rate. Everyone who lives long enough will experience at least one eye disease in their lifetime.

2.1.1. Data for Bulgaria

In Bulgaria, no regular epidemiological studies have been carried out, which is why we usually refer to European and global data on the incidence of various diseases.

In 1995, a large-scale study on ocular morbidity was carried out by Acad. P. Vassileva and a team, in Sofia and Western Bulgaria. Examined were 6275 randomly selected patients over the age of 40. Identified were the main causes for vision loss: 20% cataracts, 20% glaucoma, 20% macular degeneration, 7% diabetic retinopathy, the rest being a combination of several eye diseases etc.

Among children in Bulgaria:

A 2015 study carried out by Dr. Kirilova, included 1/5 of all 1 437 (21%) pre-school and school age children registered in Poduene district of Sofia. For 95% of children, the screening was during a primary examination with an ophthalmologist. 9.05% showed decreased visual acuity of both eyes and in 9.53% of the children detected was a risk of amblyopia. 8.84% of all children were found to have abnormalities in stereo vision and 3.7% were with male gender correlated color perception disturbances.

In 2007-2009, N.Veleva examined institutionalized children and children from auxiliary schools on the territory of Sofia with normal and delayed neuropsychological development. The presence of ocular pathology was found in 35% of the children with normal development and 55% of the children with delayed neuropsychological development. A serious impairment of one or both eyes or blindness was found in 2.5% of the children in the first group and 11.7% in the second group.

Isolated studies by A. Oscar and a team at the Alexandrovska Hospital, in the period 2013-2015, among children in preschool and school age from northeastern Bulgaria, found that 90% of these children / between 6 and 12 years old/ had not been examined by an ophthalmologist and established an amblyopia rate of 4.85%. The same team of researchers found, in the course of prophylactic examinations of children between 4 and 8 years old on the territory of Sofia, that 50% of the teenagers had been consulted by a specialist and the incidence of amblyopia was about 4%.

A study conducted 2015 - 2016 by M. Dragomirova, which analyzed the results of 1,227 school-age children, as part of a campaign to prevent childhood vision, showed that:

- 56.7% of the children had never had eye examinations
- 35% had a visual impairment (myopia, hypermetropia or astigmatism)
- Only 15% had spectacles prescribed, and half of them declared that they did not wear them

In 2016-2017, St. Dikova conducted child examinations in the six major regions of the country (3450 children between 4 and 10 years old) and established an incidence of amblyopia between 4.23% and 5.66%.

All known studies in Bulgaria show that a very large number of children do not undergo the recommended ophthalmologist examinations. There is no effective state policy for timely detection of vision problems in children. To the extent that screenings and prevention are carried out at all, they are mainly due to NGOs, social entrepreneurship and research projects.

Among the adult population in Bulgaria:

Data on the incidence of diabetic retinopathy and diabetic macular edema among diabetics in Bulgaria can be found in the data about Europe of Diabetes Barometer – a study with geographical coverage for all regions of the world.

(The diabetic retinopathy barometer report global findings. Electronic Book; 2017).

According to the Diabetes Barometer, 50% of the people with diabetes in Bulgaria are affected by diabetic retinopathy, and the % incidence of Diabetic Macular Edema among diabetics is 25%.

Data on permanent disability due to visual impairment can be found in the 2004 publication of A. Bukov which analyzes the findings of the NEMC for the period 1998-2002.

They show a tendency for an increase in the patients with cataracts / from 15.4% to 21.19% /, a decrease in the patients with diabetic retinopathy / from 25.31% to 20.915 %/ and stability in the percentage of patients with glaucoma / 22.10%, and 22.61%/.

The data of the ocular LEMC in Varna for the northeastern Bulgaria, for the periods 2005-2008 and 2008-2012, show a decrease in the primary disability by 0.5-4 times in all age groups for the second period (B. Nencheva) which, however, correlates with the decrease of the population in the area. The leading causes of visual impairment in both urban and rural areas are trauma, cataracts, glaucoma and diabetic retinopathy.

Unfortunately, the data from the expert medical committees do not provide one hundred percent coverage of all visually impaired people because of the passive nature of their operation. A number of affected persons remain unregistered due to lack of motivation and this significantly distorts the statistics. The same applies to the lists of the Union of the Blind in Bulgaria due to its voluntary membership.

2.1.2. Data for Europe

The leading causes of visual impairment and blindness to Europe are as follows:

- In infancy and adolescence: rare eye diseases (European Commission list - ERN-EYE perimeter diseases (about 900 types of eye diseases): retinal diseases, neuroophthalmic, pediatric, of the anterior eye segment.
- At working age: Diabetic retinopathy.
- In persons over 50: Cataract, Glaucoma, ARMD, Diabetic Retinopathy.

2.2. Access and barriers to eye health care

The consumption of eye health care is uneven and is determined by the availability, accessibility, affordability and acceptability of this aid.

The shortage of trained staff is one of the most important challenges the access to eye health care faces. The territorial distribution of the trained specialists does not meet the needs of the population.
Globally, the responsibility for performing surgery and for treating all common eye diseases such as glaucoma, diabetic retinopathy, ARMD, lies with the ophthalmologists.
There is also a critical is shortage of optometrists and other types of ophthalmologists, namely, opticians, refractive specialists, orthoptists, ophthalmic nurses, assistants and others. Some of these groups represent the major professionals involved in the care for refractive anomalies worldwide.

In the sphere of ophthalmology, Bulgaria currently has:

89 hospitals which have contracts with the NHIF for hospital activity (this meaning that they are allowed to operate in surgery). These are hospitals and medical centers.
670 ophthalmologists
60-70 postgraduate students in ophthalmology
Unfortunately, no Bulgarian eye hospital, or medical center, has been designated as a center of expertise for any of the rare eye diseases. As of January 31, 2020, Bulgaria and Romania are the Central European countries which are not present with hospitals and healthcare professionals in the European Rare Eye Disease Reference Network ERN-EYE www.ern-eye.eu.

Optometrists in Bulgaria:
Global practice shows that the optometrists are a very important resource for the correction, rehabilitation and prevention of visual impairments. The WHO has included the optometrists in the group of health, but not medical, professionals. This occupational group has been identified by the WHO as a priority for development.
The optometrists in Bulgaria are a resource that has not yet been fully used. They operate in a regulatory vacuum; no regulatory framework for the scope of their practice has been adopted. The proposals made in this direction so far have been left ineffective.
There are about 220 optometrists (183 of them graduated from Sofia University by 2019 incl. + the graduates from two courses in Varna Medical University and several optometrists from universities in Germany and the UK).
Low Vision specialization opportunities are limited.
Low Vision Basic Course is included in the one-year Master's Degree Program in Optometry at Sofia University. This Master's Degree Program is for Bachelors in Optometry.

Over the last 20 years, primary vision care in Bulgaria has seen a crisis concerning the resources of trained specialists:

- Regulations require that the general practitioner should be responsible for referring children to an ophthalmologist.

- According to the National Statistical Institute, the number of general practitioners has decreased significantly over 10 years, from 5352 to 4572 (2003 - 2013).
- A 2013 study by K. Trifonova has identified significant gaps in the training of general practitioners in the field of ophthalmology. According to the study, only 59.1% of them know that amblyopia responds to treatment most effectively at preschool age. And 31.8% believe this can happen at any age.

Optometrists' involvement in the prevention and screening of vision may be noted as a positive tendency in overcoming the shortage of specialists in primary vision care. After 2015, school vision screenings are included in the compulsory practice of optometry students at Sofia University “St. Kliment Ohridski".
At the time of publication of the report, the project team did not have data on the number of visual rehabilitation centers available in the country, the number, availability and educational training of visual rehabilitation professionals, and the number of ophthalmic nurses.

Major difficulties in the ensuring medical care for eye diseases in Bulgaria:
The main difficulties in providing medical care in the field of ophthalmology are as follows:

- Lack of large-scale prophylactic screening programs for different age groups
- Difficulty in carrying out specialist examinations due to the specific healthcare system in Bulgaria

3. Dealing with eye diseases and visual impairments in Bulgaria. Regulations and strategic documents

Generally accepted are four strategies for influence (interventions) in eye diseases and visual impairments: promotion, prevention, treatment and rehabilitation.

3.1. Promotion and prevention. Regulations and strategic documents

Influence through promotion aims to help a person gain greater control over his or her eye health by raising his / her awareness and knowledge rather than by focusing on specific risk factors or diseases.
In Bulgaria, at the national level, health promotion policies are set out in strategic documents adopted and implemented by the state.
The National Health Strategy 2014-2020, for example, under Priority 3 "Strengthening public health capacity", provides for measures to promote health and prevent disease. According to the strategy: "The planning, development and implementation of health promotion policies,

integrated prevention of non-communicable diseases, surveillance of communicable diseases and effective state health controls to limit the incidence of non-communicable and communicable diseases and prevention of the adverse effects of behavioral risk factors and environmental factors are implemented at national level - by the Ministry of Health and National Centers for Public Health, and at regional level - by the Regional Health Inspectorates (RHI)."

The strategy covers, to varying degrees, the different spheres of protection and improvement of public health.

Eye diseases and visual impairments are not subject to a specific policy or measure in the National Health Strategy.

However, the National Program for the Improvement of Maternal and Child Health 2014-2020 provides for measures aimed at preventing the development and complications, incl. of eye diseases.

Operational objective 3 of the National Program provides for "Introducing screening for children with special needs with a view to preventing the development of complications", the measures being:

- Optimizing and expanding the existing prevention and screening programs for pregnant women and children;
- Developing a mechanism and introduction of neonatal auditory screening, screening for retinopathy in premature infants, etc.
- Upgrading the equipment for diagnosis of genetic diseases;
- Finishing the installation of equipment for the purposes of screening and treatment for retinopathy in the premature babies
- Updating the regulatory framework for prophylactic examinations with a view to early diagnosis of vision abnormalities in children
- Purchase of apparatus for the examination of refraction in young children of pre-verbal age

To achieve the goals of the National Program, a Work Plan (Annex 1 to the Program) has been developed, which provides for screening activities, incl. such related to eye health: developing a mechanism and introducing screening for retinopathy in premature babies ; finishing the installation of equipment for the purposes of screening and treatment for retinopathy in premature babies; updating the regulatory framework for prophylactic examinations with a view to early diagnosis of visual defects in children; purchase of refractive examination apparatus for young children at pre-verbal age. These activities are envisaged for implementation in the period 2015-2020, and they are specifically provided with funding amounting to BGN 2,350,000.

The question of the extent to which these activities have already been implemented as per 2020 remains open.

Although diabetes is one of the major chronic non-communicable diseases, the National Program for the Prevention of Chronic Non-communicable Diseases 2014-2020 does not cover the complications thereof leading to impaired ocular health.

Despite the international recommendations and European declarations, and despite the national consensus among ophthalmologists at the national level concerning the need for screening and early detection of diabetic retinopathy, no such program is current in Bulgaria.

3.2. Treatment

The Bulgarian Society of Ophthalmology has made recommendations for good medical practice in cataracts, diabetic retinopathy, age-related macular degeneration, glaucoma, retinal venous occlusions, preterm retinopathy, complete eye examination.
In the list of rare diseases established in the Republic of Bulgaria by Ordinance No.16/ 30.07.2014 of the Minister of Health On the conditions and procedure for registering rare diseases and for the centers of expertise and reference networks for rare diseases, none of the 900 rare eye diseases – the leading cause of visual impairment and blindness in childhood and adolescence - is present, which determines the absence of algorithms for diagnosis, including genetic testing and genetic counselling, treatment, follow-up and rehabilitation of patients with such diseases.

3.3. Rehabilitation

"Rehabilitation" is a consistent and continuous recovery process that helps a disabled person to achieve an optimal physical, intellectual, mental and social level of activity, providing him with opportunities to change his life to a greater degree of independence. This definition is given in § 1, item 7 of the supplementary provisions of the Persons with Disabilities Act (PDA).
Art.29 et seq. of the same law defines rehabilitation as the right of a disabled person; it may be complex and may include medical, professional, social, occupational and psychological rehabilitation.
Directly connected with the right to rehabilitation is also the right of people with disabilities to assistive devices and medical devices. The terms and conditions for the granting of aids and medical devices are laid down in the implementing rules of the PDA. The medical conditions, operating periods and necessary medical documents for the provision of aids, devices, facilities and medical devices for which financial assistance is targeted towards persons with disabilities with special needs, according to the type of disability and the individual needs assessment, are listed in Annex No. 2 to Art.68, Para.1 of the Rules.
The types and number of aids for the visually impaired, the limits and requirements set for them, are not found to meet the actual needs of the disabled. As a result, people with visual impairments cannot fully enjoy their right to rehabilitation.

Main conclusions

The following conclusions can be drawn from the information collected and the analysis performed on the report:

1. There is a lack of reliable statistical information on the number of people with visual impairments in Bulgaria, which impedes the formation and implementation of adequate state policies in this field.
2. Although the prevailing causes for visual impairment and blindness in Bulgaria are known, well-established medical practices for overcoming them have not been adopted and are being applied only to some of them.
3. There are no comprehensive and detailed legal and policy documents for dealing with visual impairments through promotion, prevention, treatment and rehabilitation.
4. There are no established and accepted minimum standards for dealing with low vision and blindness.

The report on the state of visual health in Bulgaria was prepared with the help of the expert team on the Vision for Vision project, composed of:

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